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BREATHING IN A NEW ERA:
a comparative analysis of
lung cancer policies across Europe

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About this report

“A breath of fresh air: a comparative analysis of lung cancer policies across Europe” is a report by The Economist Intelligence Unit (EIU) that examines the burden of lung cancer in Europe and how countries are responding to its challenge.

The research centres on assessing unmet needs within health systems and opportunities for improvement. We analyse how countries can build awareness, improve prevention, early detection, diagnosis and prognosis, and ensure access to high-quality treatment—including supportive and palliative care. Key to good practice for many of these activities is ensuring that the patient voice is heard, including through the role of patient organisations.

Our goal is to identify and improve outcomes for those with lung cancer across Europe. We hope to do this by helping to provide the impetus for the improvement of cancer plans and national policies. The use of a benchmarking scorecard allows countries to see how they are performing compared to their peers and to then use that insight to drive change at home.

The EIU carried out an evidence review and convened an advisory board to help design a scorecard of the key building blocks of good practice in health policy and system development in the field of lung cancer. Alongside this, EIU researchers attended national workshops featuring a mixture of stakeholders to understand national-level challenges. Resulting from these, and published alongside this policy paper, are a series of country profiles.

The research programme was sponsored by MSD. We would like to thank the following individuals and organisations for sharing their insight and experience.

- Mr **Alfonso Aguarón**, Project Manager, Lung Cancer Europe (LUCE), Spain
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- Dr **Ioannis Boukovinas**, MD, PhD, Head of the Bioclinic Oncology Unit of Thessaloniki, Greece
- Professor **John Field**, Director of Research, Roy Castle Lung Cancer Research Programme, University of Liverpool, UK
- Dr **Marina Garassino**, MD, National Cancer Institute of Milan, Italy
- Professor **Pilar Garrido**, Head of Thoracic Tumours Unit, University Hospital Ramón y Cajal (IRYCIS), Spain

The Economist Intelligence Unit bears sole responsibility for the content of this report. The findings and views expressed in the report do not necessarily reflect the views of the sponsor. The EIU team involved in this report consisted of Mary Bussell, Darshni Nagaria, Anelia Boshnakova and Alan Lovell.

Executive summary

Lung cancer has the highest incidence and mortality of all cancers. While 200 different types of cancer are the cause of one in six deaths, one in five of these cancer deaths are caused by lung cancer, in spite of it being a largely preventable disease. Although there has been important progress in recent years, lung cancer remains amongst the deadliest types of cancer, with a high disease burden and variability in medical need. And incidence continues to rise remorselessly: between 2012 and 2018 the number of new lung cancer diagnoses increased from 1.8 million to 2 million worldwide. Yet, historically, lung cancer has not had the attention it deserves. In Europe, the spend to burden ratio remains much lower for lung cancer than for other major cancers such as breast, colorectal or prostate cancer.

Poor outcomes for lung cancer patients have stemmed from several factors, including late diagnosis, poor access to treatment, and a mixture of fatalism and stigma. With new treatment options arriving on the scene it is an appropriate time to review the current picture of disease burden, investigate unmet needs and recommend improvements to how health systems currently manage lung cancer. Following an evidence-based approach, incorporating an evidence review and advisory board, we designed a policy scorecard to assess current policy and systems performance across five domains:

- **Lung cancer is a strategic priority:** focusing on control plans and guidelines
- **Lung cancer is a public health issue:** covering tobacco control and screening
- **Lung cancer is a race against time:** rapid diagnosis and fast-track referral
- **Lung cancer is at a crossroads:** on effective treatment and quality care
- **Lung cancer is a focus for research:** investing in registries and R&D

Indicators within each domain were selected based on evidence of their association with improved outcomes. After drafting scores for indicators within these five domains from the published and grey literature, we then attended national workshops to validate our scores and flesh out opportunities for improvement in each country. In addition to this report each country has a country profile detailing national data on epidemiology and spend, scores for each indicator and a list of recommendations. There are two phases of our study in Europe: this first phase includes 11 countries. The second phase will cover a further 16 countries.

Our findings show that while good practice exists, there is room for improvement across all countries and all domains. This includes ensuring that there are fast-track referral pathways, effective psychological support services, strong public health regulations and access to high-quality treatment. Comprehensive and up to date national cancer control plans can be used to guide these improvements, and registries with clinical data—such as stage and pathology at diagnosis, treatment received, and patient reported outcome measures—will help to evaluate implementation.

Health outcomes are influenced by a range of factors, only some of which can be impacted by policy. There is often a time lag between policy implementation and impact. We should not, therefore,

expect to always see a correlation between current outcomes and best practice—as measured by the scorecard. However, because of the evidence base behind the scorecard, we would expect to see improvements in lung cancer outcomes over time in countries that implement the scored policies.

The report concludes with five regional calls to action:

An improvement in strategic planning and the means to collect data to inform it

National Cancer Control Plans and lung cancer specific control plans should be in place, regularly updated and properly funded. These plans will form a basis on how a country addresses cancer care. Countries with devolved health systems need to find workable solutions to ensure that the National Cancer Control Plan can be adopted to ensure the delivery of equitable care across every region in a country.

A renewed focus on early detection, including an assessment of the pros and cons of a national screening programme

Lung cancer guidelines should encompass clear referral pathways, timeframes and quality indicators. Timeframes—often overlooked—must be embedded within the guidelines, as they serve as benchmarks to evaluate performance. Time is of the essence for lung cancer patients, as referral and diagnosis is often delayed. Similarly, screening programmes should be considered in an evidence-based manner. Increased awareness and availability of screening services among the public and among primary care providers may help to address unmet needs.

Put patients front and centre, and ensure that they are heard by decision makers

Although many health systems have taken steps in the right direction, most countries could do more to involve patients (and patient organisations) in decision making. The inclusion of patient organisations in national assessments of disease and policy development can help to build consensus.

Create systems to ensure sustainable and equitable access to innovations

Medical innovations and new technologies have added to the range of treatment options for lung cancer patients; improved survival and better quality of life is within reach for some. Ensuring access to biomarker testing and enabling patients to access innovative therapies will require new processes and systems—possibly involving risk sharing. New innovations promise much, but stakeholders need to work together to get them to patients.

De-stigmatise the disease through education, awareness and compassion

Reducing negative attitudes and fatalistic thinking, while promoting anti-smoking efforts, can help to reduce stigma at a professional level and in society at large. It is encouraging that several countries are looking into how stigma and its associated barriers to good quality care can be reduced. Certainly, other diseases with negative stigmas have been successfully de-stigmatised, including other cancers. The strategies used for other diseases may be adapted for use in lung cancer. It is time that all people with lung cancer are treated with compassion and dignity.

Introduction

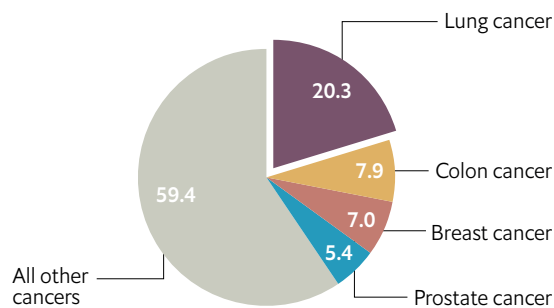
The deadliest cancer

Cancer causes one in six deaths. One in five of these cancer deaths is due to lung cancer, in spite of it being a largely preventable disease.¹ Survival rates are not only low but also vary significantly: in Western countries, five-year survival rates average 15%.² These poor outcomes stem from a number of factors including late diagnosis, poor access to treatment, and a mixture of stigma and fatalism. Today in Europe, mortality from lung cancer is equal to the mortality from breast, colon and prostate cancer combined (Figure 1).

The global incidence of lung cancer is increasing: in 2018, there were 2 million new cases of lung cancer, an increase from 1.8 million new cases in 2012.¹ Lung cancer is more common in men, among whom the highest incidence rates are in Central and Eastern Europe, along with Eastern Asia. In women, lung cancer is the third most commonly occurring cancer, and the highest rates are in Northern Europe, Eastern Asia and North America.¹ Survival is largely dependent on the stage at which lung cancer is diagnosed: the earlier the diagnosis, the better the prognosis.

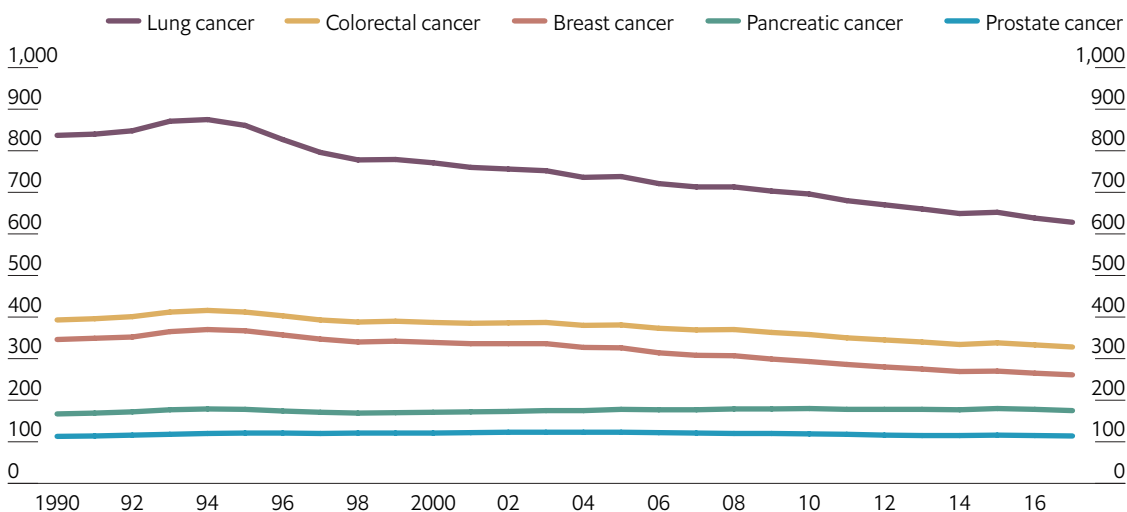
The burden of a disease can be measured by comparing disability-adjusted life years (DALYs). A DALY can be thought of as one lost year of

Figure 1: Top 4 causes of cancer mortality (%)



Source Globocan, 2018.

Figure 2: DALYs among top 5 cancers in Europe (rate per 100,000)



Source: Global Burden of Disease, 2017.

“healthy” life; the higher the DALY, the greater the burden. DALYs take into consideration the years of life lost due to a) premature mortality and b) morbidity (that is, disability and ill health). Although lung cancer has a significantly higher burden in Europe than colorectal cancer, breast cancer, pancreatic cancer and prostate cancer, its burden has dropped more than the other four cancers over the last couple of decades—partly owing to a fall in rates of smoking over the same period (Figure 2).³

Poverty and ignorance: twin drivers of lung cancer

Growing and aging populations, urbanisation and lifestyle changes have resulted in an increasing global burden from cancers as a whole. And although socioeconomic status is linked to cancer generally, it plays a particularly strong role in lung cancer.

Socioeconomic status is the social standing or class of an individual or group—often measured as a combination of education, income and occupation. People with low socioeconomic status are more likely to engage in unhealthy behaviours, such as smoking: in the UK, 23% of people in the lowest income band smoke, versus 11% of those with incomes over £40,000.⁴

This high incidence of unhealthy behaviours is often compounded by poor treatment. The UK's National Lung Cancer Audit documents significant inequalities in treatment due to regional variations between England and Wales.⁵ People with low socioeconomic status also on average have lower health literacy (that is, the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions).⁶ And low health literacy means that people are likely to be particularly immune to public health messages and awareness campaigns. Indeed, the existence of low health literacy is a challenge throughout Europe.⁷ There is, therefore, a need for public health and health promotion activities that target specific hard-to-reach populations.

The association between low socioeconomic status and lung cancer emerges clearly in national statistics. In England and Scotland there is a nearly threefold greater incidence among the most deprived versus the least deprived populations.^{8,9} The Independent Cancer Task Force in England concluded that if socioeconomically disadvantaged populations in the country had the same incidence rates as the least deprived, there would be 11,700 fewer cases of lung cancer each year.¹⁰ Similar inequities have been documented in Norway and a number of other European countries.¹¹

Lung cancer is responsible for 15% of all cancer costs in Europe

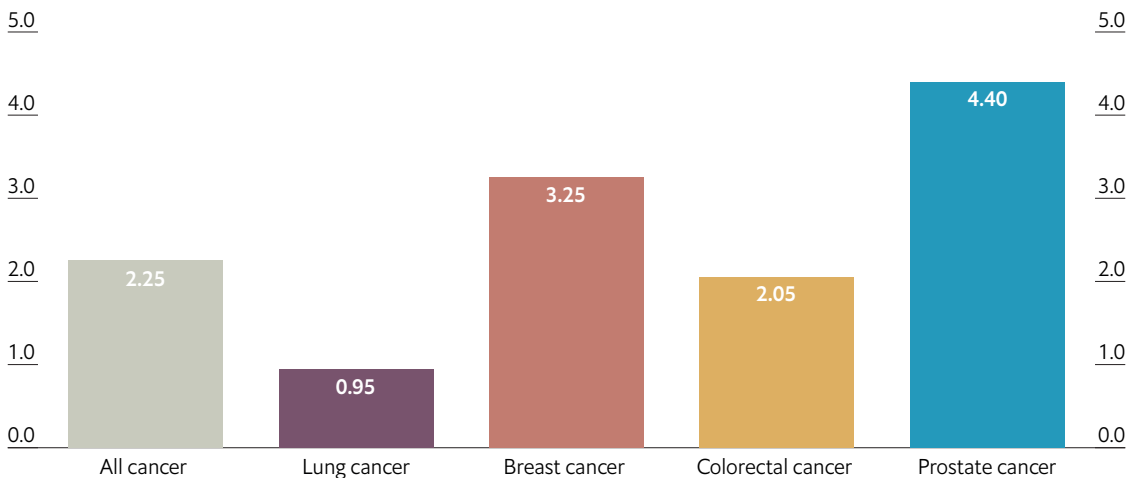
Cancer is estimated to cost Europe about €126 billion (US\$140 billion) per year—with €52 billion due to lost productivity.¹² As advances in healthcare extend life expectancy and as populations grow and age, this cost will continue to grow.¹³ Lung cancer has a larger economic burden (calculated as the sum of direct healthcare costs and indirect costs such as lost productivity) than breast, colorectal and prostate cancer combined.¹² In 2009 lung cancer consumed 15% of overall cancer costs in Europe, at a price tag of US\$18.8 billion.¹⁴

Although the cost of treating lung cancer comes with a hefty price tag, it is still arguably relatively under-resourced. The proportion of government health expenditure allocated to each individual cancer is not proportionate to its burden.¹⁵ While on average approximately 5% of all health expenditure is for cancer, there is a significant difference between what is spent on different types of

cancer.¹² Historically, the spend to burden ratio has been found to be much lower for lung cancer than for breast, colorectal or prostate cancers in Europe (Figure 3).¹² It is uncertain why this is the case. The lack of expensive national screening programmes for lung cancer may explain part of this relatively low spend; the stigma of lung cancer may, subconsciously, contribute too.

Figure 3: Spend to disease burden - top 4 cancers, Europe

(Ratio of spend to burden; € thousand per DALY lost)



Source: Office of Health Economics (OHE) Consulting and Swedish Institute for Health Economics (IHE), September 2016.

The research project and its goals

Our research is in two phases. This document covers the first phase of our research, in which we analyse 11 countries: Austria, Belgium, Finland, France, the Netherlands, Norway, Poland, Romania, Spain, Sweden and the UK. Germany and Greece were originally part of this phase but, owing to scheduling challenges, will now be included in phase two, along with 14 additional countries. Phase two will be published in early 2020. Upon completion of phase two, we will have analysed 26 European countries and Israel (Figure 4). Countries in phase one are all either upper-middle-income or high-income economies.

In brief, we performed an initial literature review to identify key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed and an editorial advisory board was convened to review and advise on the development of the indicator framework. Out of this process, we identified a set of 17 indicators to evaluate each country across five domains:

- Lung cancer is a strategic priority: focusing on control plans and guidelines
- Lung cancer is a public health issue: covering tobacco control and screening
- Lung cancer is a race against time: rapid diagnosis and fast-track referral
- Lung cancer is at a crossroads: on effective treatment and quality care
- Lung cancer is a focus for research: investing in registries and R&D

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A COMPARATIVE ANALYSIS OF LUNG CANCER POLICIES ACROSS EUROPE

Figure 4: map of countries in phase 1 (this report) and phase 2 (to be published in 2020)



A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. After draft scores were assigned, the EIU attended a workshop in each country with external country-based experts, to discuss the findings and help develop our recommendations. Throughout the process, the EIU retained editorial control, so all final decisions and conclusions are ours alone. When we wish to refer to the main emergent themes of one or more workshop we will refer to input of workshop “participants”.

See the appendices for the full methods, the scorecard and the list of workshop participants.

How do we know what we are measuring is meaningful?

The theoretical basis of the scorecard is that indicators measure policy and system factors that are associated with improved outcomes. The logical consequence of this is that if countries implement what the scorecard is measuring, over time they will see reduced incidence and improved survival. Of course, outcomes are driven by a number of factors, and there are always numerous confounders to consider. Nevertheless, for some indicators there is good quality evidence that they are associated with improved outcomes.

For example, there is published evidence that access to radiotherapy is significantly associated with improved survival¹⁶ and that quitting smoking can decrease lung cancer risk even among those genetically predisposed to it.¹⁷ Also, a systematic review concluded that lung cancer specific stigma

has been associated with lower self-esteem, lower social support, poorer social integration and higher social conflict¹⁸—all of which are in turn associated with poorer health outcomes. And although early supportive care for lung cancer patients can lead to significant improvements in quality of life, mood and survival,¹⁹ lung cancer specialists complain that patients are often not referred to supportive and palliative care services until very late on in their care.²⁰ These evidence sources all contributed to the development of indicators.

On other occasions—particularly where the evidence is less clear cut—we follow recommendations from authoritative organisations and individuals. For example, Lung Cancer Europe recommends raising lung cancer awareness among general practitioners, and that this should include increased training and a fast-track referral process.²¹ In terms of the need to support the input of patient groups into decision making, Professor Jean-Paul Sculier of the European Respiratory Society has remarked that advocacy for lung cancer research and funding may be lagging behind other cancers because survival rates are so low, and so patients are unable to advocate.²² For all indicators, and for the structure of the scorecard itself, we leant on the advice and guidance of the advisory panel—although all decisions were ultimately made by the EIU project team.

The goal of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country. We hope to do this by helping to provide the impetus for the development of national policies and encouragement of best practice.

Epidemiology

Sweden has the lowest burden, Poland the highest

Table 1 shows 2017 estimates of age-standardised incidence, prevalence, disability adjusted life years (DALYs) and mortality rates for lung cancer in 11 European countries.²³ The incidence rate is the number of new cases of lung cancer in a given year. The prevalence rate is the number of lung cancer cases that are present in the general population of a country in a given year. Sweden has the lowest incidence rate, the joint-lowest prevalence rate (with Romania), the lowest number of DALYs and the lowest mortality rate. The Netherlands has the highest incidence rate and prevalence rate, while Poland has the highest number of DALYs and the highest mortality rate.

Table 1: Comparative epidemiology of phase 1 countries

Red and green colours show highest and lowest national figures, respectively

Country	Incidence rate (per 100,00)	Prevalence rate (per 100,000)	DALYs rate (per 100,000)	Mortality rate (per 100,000)
Austria	33	67	549	24
Belgium	37	56	711	32
Finland	25	47	402	20
France	34	49	707	29
Netherlands	44	79	767	36
Norway	30	66	467	22
Poland	37	40	890	39
Romania	30	32	760	30
Spain	33	67	568	25
Sweden	21	32	373	19
United Kingdom	40	77	599	30
Europe	33	54	628	27
Global	27	42	503	24

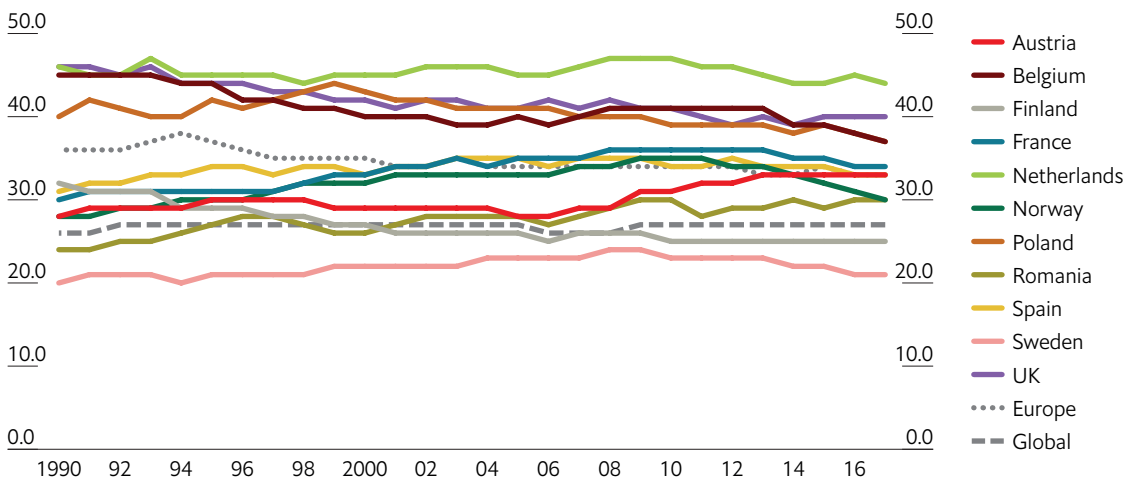
Source: Global Burden of Disease, 2017.

Epidemiological trends in Europe paint a mixed picture

Figure 5 shows lung cancer incidence rates over the last 27 years; our countries fall within a range of between 23 and 55 cases per 100,000 per year. Sweden appears to have consistently low incidence rates in comparison with the other countries, whereas the Netherlands has a consistently elevated rate. Otherwise, the picture is mixed. For example, Norway and Romania have experienced upward trends, while Belgium and Finland have seen significant falls. Until 2011, the UK also had declining rates, but since then the rate has stabilised.

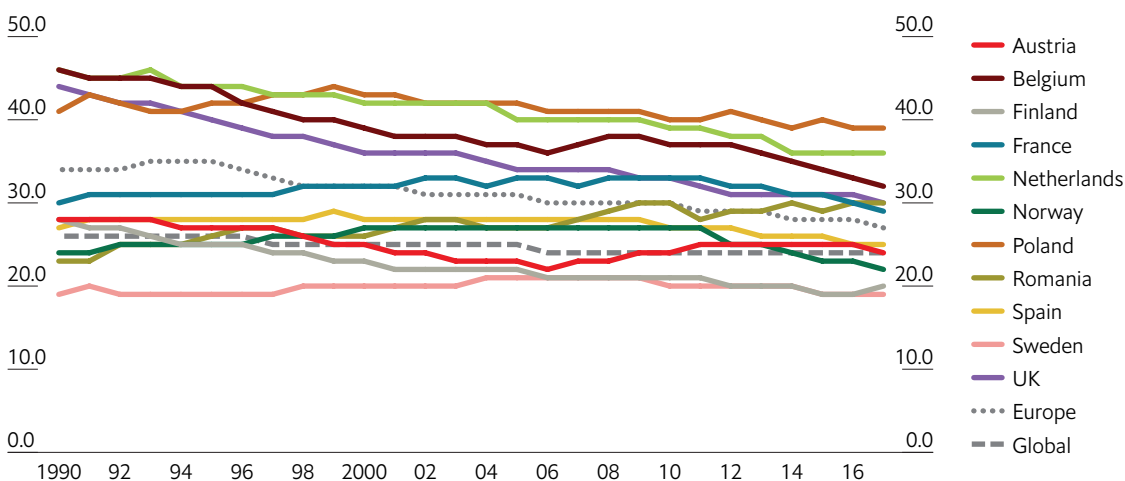
In terms of mortality, lung cancer is the biggest cancer killer in Europe.²⁴ Figure 6 shows mortality rates. Many countries with previously high mortality rates, such as Belgium, the UK and the

Figure 5: Lung cancer incidence rates, 1990-2017
(rate per 100,000)



Source: Global Burden of Disease, 2017.

Figure 6: Lung cancer mortality rates, 1990-2017
(rate per 100,000)



Source: Global Burden of Disease, 2017.

BREATHING IN A NEW ERA

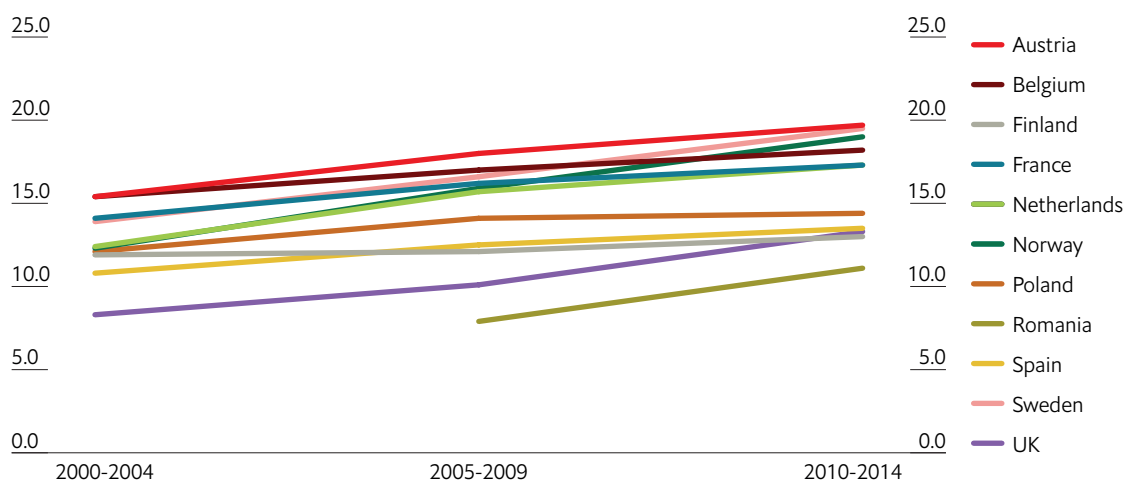
A COMPARATIVE ANALYSIS OF LUNG CANCER POLICIES ACROSS EUROPE

Netherlands, have seen their rates fall over the years, leading to Poland having the highest rate today. Sweden has consistently had the lowest rate, although Finland is now running a close second.

Figure 7 depicts average five-year survival rates of adults with lung cancer for each country from three time periods: 2000-04, 2005-09 and 2010-14.²⁵ All countries show an upward trend, with Sweden and Norway having the steepest increases in survival (although compared with most other cancers, survival rates remain frustratingly low: five-year survival for both breast and prostate cancers exceed 80%). Although Romania's survival rates are lower than the other ten countries, they do follow a positive trend. Austria has continually had the highest five-year survival results. In 2010-14, the five-year survival rate was 19.7%.

Figure 7: Lung cancer 5-year survival rate

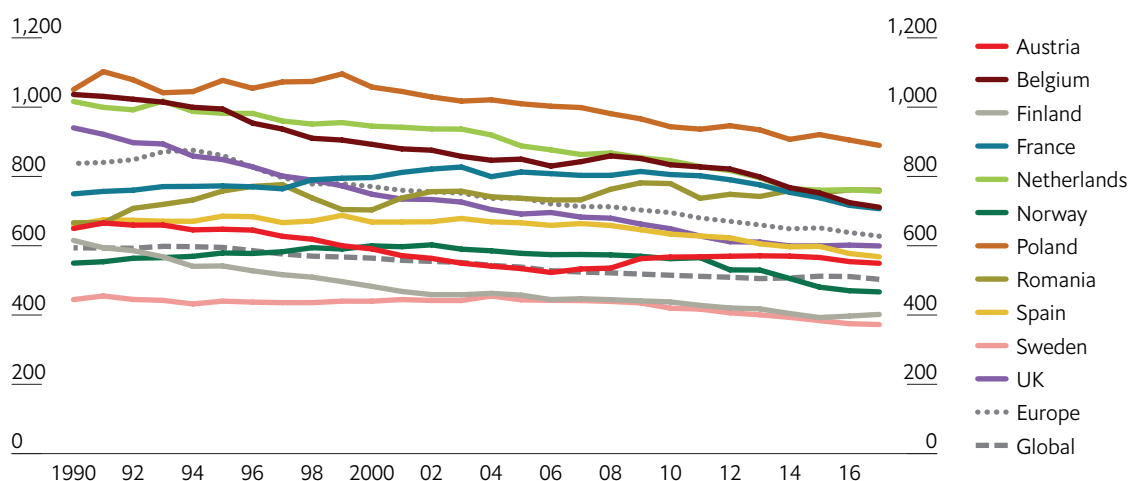
(adults 15-99 years, age standardised, %)



Source: CONCORD-3, 2018.

Figure 8: Lung cancer DALY rates, 1990-2017

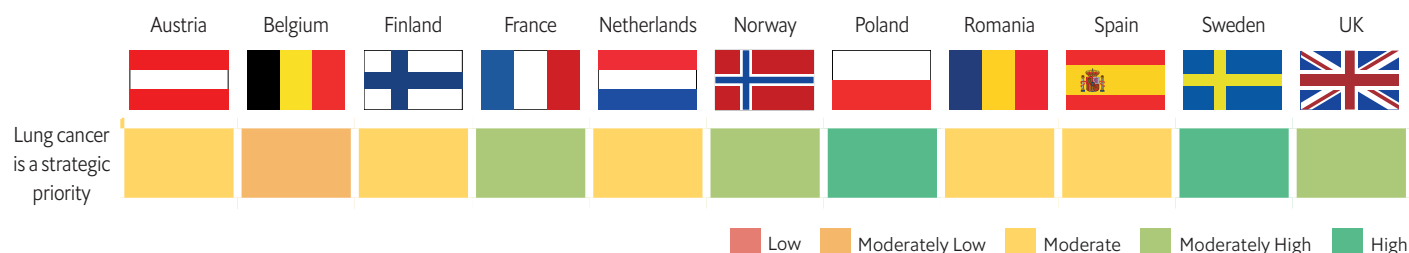
(rate per 100,000)



Source: Global Burden of Disease, 2017.

Lung cancer burden over time, captured via DALYs, is shown in Figure 8. All countries show a consistently downward trend, although Romania has had fluctuating DALY rates over the past 15 years. Poland has continually recorded the highest burden rate, while Sweden, again, has recorded the lowest. Belgium, the Netherlands, Poland and the UK have had steep declines in DALY rates.

Lung cancer is a strategic priority



The strategic priority domain covers national cancer control plans and the use of guidelines. Although guidelines are arguably operational documents, we included them here, as they can also be “agenda-setting” when it comes to incorporating new technologies for diagnosis and treatment. Poland and Sweden performed to a high standard; France, Norway and the UK performed moderately well. Belgium performed relatively poorly.

National Cancer Control Plans are the basis of co-ordinated action

A National Cancer Control Plan is a document produced by a government or health ministry. It sets out a nation’s strategies for addressing the burden of cancer through the prioritisation and co-ordination of programmes—including awareness, prevention, early detection and treatment. High-quality National Cancer Control Plans are regularly updated, realistic and goal-oriented, with a detailed implementation plan, and an appropriate, sufficient and clearly identified source of funding.

National Cancer Control Plans exist in ten of our eleven countries. Romania does not currently have a plan, although one is in production. Of the ten countries with a plan, six have been updated within the past five years. Austria, Belgium, the Netherlands and Spain have out of date plans—although Spain has developed a revised plan that has not yet been endorsed by the government. Even in countries with plans, we noted that participants were often unsatisfied with progress. For example, although the Swedish national plan was updated in 2018, participants suggested that better regional collaboration on the ground was needed to—for example—improve access to care for lung cancer patients. In Norway, the updated plan did not identify a source of funding, and participants questioned its usefulness.

Alongside a national cancer control plan, a specific lung cancer control plan can add nuance and detail to lung cancer needs. Such a plan also helps to demonstrate a country’s commitment to addressing the disease. Of the included countries, only Poland has a lung cancer specific plan.

Clinical guidelines (remain) varied in both quality and scope

Clinical guidelines are generally produced by medical societies to guide the treatment of a disease and formalise standards of care. When they are developed at a national level they can help to minimise

regional discrepancies by establishing national benchmarks. A high-quality, evidence-based clinical guideline will cover the continuum of care, ranging from screening and early detection through to diagnosis, treatment and psychological support, as well as supportive and palliative care. Ideally, guidelines will also describe the working of multidisciplinary care teams and ensure that there is a role for patient involvement, for example through shared decision-making. To this end, including patient organisations in the development of clinical guidelines can help to prioritise what matters to the patient and identify issues that may otherwise be overlooked by health professionals.

Our analysis of national lung cancer guidelines revealed significant variation in both quality and coverage. Recognition of the mental burden and ways to access psychological support were often lacking. Similarly, although lung cancer is a disease that needs to be addressed with urgency, many guidelines did not adequately describe fast-tracking of suspected patients or set out a specific timeframe within which a diagnostic referral should be made. Also, guidelines often did not include a pathway for rapid referral for patients to obtain secondary or tertiary care.

A 2014 review of 56 European lung cancer guidelines found that, while the guidelines covered showed some areas of duplication, they differed markedly in scope and content.²⁶ Five years later, we draw a similar conclusion. Each country we analysed uses lung cancer clinical guidelines and all of these discuss diagnosis and treatment. However, only seven countries' guidelines discuss shared decision-making: Austria, France, the Netherlands, Norway, Romania, Sweden and the UK. Ten of eleven countries' guidelines discuss supportive and palliative care; Belgium's does not. Screening is only discussed in guidelines produced by six of the eleven countries—Finland, the Netherlands, Norway, Poland, Romania and Sweden—although discussion of screening in the guidelines does not necessarily mean that the country has a national screening programme.

Fresh thinking: opportunities for improvement

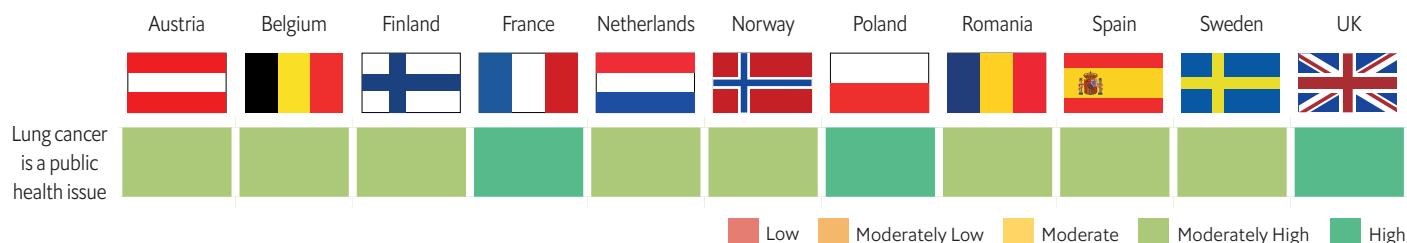
Keeping plans up to date. Lung cancer is a complex, fast-moving area of research, with new technologies constantly coming on-line. Although drawing up a high-quality plan may seem a substantial investment, to be effective plans need to be kept up to date and periodically refreshed or replaced.

Implementation of plans. Most countries did not discuss how their plans were going to be funded. Such an omission puts implementation at

risk, particularly during times of austerity. Funding for a national cancer control plan should be both sufficient and ring-fenced to ensure that the plan can meet its objectives. An implementation and evaluation framework should also be included.

The patient voice in the development of guidelines. The fact that shared decision making and psychological support was missing in many countries' guidelines suggest that the patient voice is not being heard. Patient involvement in the development of guidelines will help ensure they remain focussed on their primary goal: the delivery of high-quality, patient-centred care.

Lung cancer is a public health issue



The public health domain covers awareness, prevention, screening and the role of patient input in policy formation. All 11 countries performed highly or moderately highly in this domain—scores are high because many indicators referred to anti-smoking legislation, which is now common in much of Europe. However, important differences are found in matters such as screening and patient involvement. France, Poland and the UK performed the best; other countries performed moderately well.

Feelings of guilt often delay diagnosis

Identifying lung cancer can be challenging, as people often present with a range of non-specific symptoms, including cough, shortness of breath, loss of weight and fatigue.²⁷ Symptom awareness campaigns hold relevance not only for the public but also primary care professionals. Oncologists and pulmonologists participating in the country workshops expressed the importance of partnering with their primary care colleagues to raise awareness and improve early detection.

A particular challenge of lung cancer is that many sufferers may feel guilt, and so delay seeking medical attention. Indeed, many lung cancer patients report being aware of their symptoms for varying periods of time before seeing a clinician.²⁸ Insight into patients' perspectives on their condition may help primary care providers to recognise potential patients with lung cancer more quickly, and so speed their referral for diagnosis and treatment.²⁹

Population screening shows potential but remains controversial

Screening for disease in the general population—with a focus on high-risk groups—is often controversial. The risks associated with population screening include subjecting people to invasive tests, the potential for false positive results and over-diagnosis. Lung cancer is no exception.³⁰ However, the prognosis for the late diagnosis of lung cancer is dismal. One-year survival for lung cancer patients diagnosed via emergency presentation is 11% (versus 28.6% for patients identified through other routes). Nevertheless, emergency presentation remains common; for example, this is how 38% of lung cancer cases in England are identified.³¹

Clinical trials focused on low-dose computed tomography (LDCT) screening of high-risk populations have been conducted in Belgium and the Netherlands (the NELSON trial), the UK, and France. The use of LDCT scans has shown a reduction in lung cancer mortality in the NELSON trial, as well as the US-

based National Lung Screening Trial, the International Early Lung Cancer Programme and a pilot study in Manchester in the UK (Box 1). Interestingly, despite clinical trials having been conducted, neither Belgium, France nor the UK discuss screening programmes in their guidelines. An increase in the range of treatment options for lung cancer has led some to re-examine their approach to screening. National debates on screening are largely fuelled, however, by concerns over staffing challenges, how to cope with an increase in the number of new diagnoses, and worries over radiation dosage, over-diagnosis and cost-effectiveness.

Box 1

NELSON study

The NELSON study³² is the largest European randomised controlled trial to demonstrate a reduction in lung cancer mortality with computed tomography (CT) screening in people at high-risk for the disease. Individuals were recruited from population-based registries in Belgium and the Netherlands. The study compared groups that offered screening with CT with those not screened. Subjects were followed for ten years.

National Lung Screening Trial

The National Lung Screening Trial³³ is a United States-based clinical trial supported by the National Cancer Institute and conducted by the American College of Radiology Imaging Network and Lung Screening Study Group.

International Early Lung Cancer Action Programme

The International Early Lung Cancer Action Programme³⁴ grew out of the benefits stemming from the Early Lung Cancer Action Programme³⁵ which started in New York in 1992 studying the benefit of annual CT screening for lung cancer. The New York study demonstrated that CT screening identified a high proportion of lung cancer in Stage 1.

Manchester's Lung Health Check

The North Manchester pilot³⁶ quadrupled the rate of early diagnosis for lung cancer in Manchester, UK. In March 2019 it was expanded into a four-year, ten-site intervention targeting those at high-risk for lung cancer. CT scans will take place in mobile units or in hospitals.

Still lighting up: Europe smokes more than anywhere else

Tobacco is recognised as the most important risk factor for all cancers, responsible for approximately 22% of cancer deaths and 85% of lung cancer cases.^{37,38,39} The “tobacco epidemic”, as it has been called by the World Health Organisation (WHO), ranks as one of the largest challenges to global public health. Worldwide, it has been estimated that 1.3 billion people currently use tobacco products—approximately 1 billion men and 250 million women.⁴⁰ Europe has the highest prevalence of tobacco smoking among adults (Table 2) and some of the highest prevalence of tobacco use by adolescents; in the Czech Republic, tobacco use in adolescents is similar to that in adults.^{41,42} The cost of this tobacco epidemic is immense: the annual social and economic costs directly attributable to tobacco consumption within the EU were estimated to be €363 billion in 2012, equivalent to 3.4% of EU27 GDP.⁴³ Of this, the highest cost directly attributable to smoking is cancer, particularly lung cancer.⁴³

Table 2: Current tobacco smoking in Europe			
WHO region	Male prevalence	Female prevalence	Both sexes
Europe	38%	19%	28%
Western Pacific	48%	3%	26%
Eastern Mediterranean	37%	3%	20%
America	22%	13%	17%
South-East Asia	32%	2%	17%
Africa	25%	2%	13%
Global	36%	7%	21%

Source: WHO, report on the global tobacco epidemic, 2015.

In many of the countries in our study, tobacco control programmes need to be strengthened. For example, several countries have only partial bans on smoking, and some have no smoke-free legislation in place. For example, Belgium has banned smoking on public transport but not in offices, or in restaurants, cafes, pubs or bars. The opposite situation is found in Finland, where smoking is banned in offices and various eateries, but not on public transport. The Netherlands has enforced no smoking bans in any of the areas we studied.*

On the plus side, a national agency for tobacco control exists in all 11 countries, and each country has signed up to the WHO's Framework Convention on Tobacco Control. Likewise, national advertising bans for tobacco exist in all countries, and mandatory health warnings must appear on all tobacco packages in each country. However, anti-tobacco mass-media campaigns were not conducted during the 2014-16 period in Belgium, Finland, Spain and Sweden.

Electronic cigarettes: help or hindrance?

Electronic cigarettes, or e-cigarettes, are devices that simulate smoking without burning tobacco. There is some evidence that they help adult smokers to quit smoking, though their benefit has not been shown to be greater than smoking cessation medication.⁴⁴ The long-term health impact of using e-cigarettes (vaping) is unknown, and some have expressed concern that usage may lead to tobacco use in teens. This presents several challenges for health professionals and policymakers. Are e-cigarettes to be welcomed, or are we in danger of a new epidemic? Certainly, the view of our advisory panel was the latter. E-cigarette use needs to be strictly regulated.

Policies on e-cigarette availability and usage vary widely across our countries; this is an area that is rapidly evolving, and policymakers have to act somewhat in the dark. However, e-cigarettes are regulated in some form in each country. Sales of e-cigarettes to people under a specific age (usually 16 or 18 years of age) are banned in nine of our countries, but not in Romania or Spain. E-cigarette advertising is banned in nine countries, but not in the Netherlands or the UK. Five countries ban e-cigarette use in public areas—the six who do not are Finland, the Netherlands, Romania, Spain, Sweden and the UK.

* We did not award a score when smoking rooms are allowed. Allowing such rooms dilutes the effectiveness of smoking bans.

Smoking is not the only cause

Although most cases of lung cancer result from tobacco use, it is not the sole cause. For example, long-term exposure to radon is a risk factor for lung cancer; it may in fact be the second leading cause, and have a synergistic effect with smoking.⁴⁵ This stems from domestic exposure arising from the diffusion of radon from the soil; as radon gas decays, tiny radioactive elements can lodge in the lung and emit radiation.⁴⁶ In order to help minimise exposure to radon, radon control policies exist in nine of our countries. Poland and Spain are the exceptions.

Lung cancer can also be the result of air pollution from both the general and work environment. As air quality deteriorates, rates of non-communicable diseases, including lung cancer, increase: air pollution is the fourth-leading fatal health risk, responsible for one in ten deaths.⁴⁷ The WHO reports that 90% of people worldwide breathe polluted air.⁴⁸ In 2013, air pollution cost the global economy approximately US\$225 billion owing to lost labour income and about US\$5.1 trillion in welfare losses due to premature death. This translates to amounts comparable to the combined gross domestic product (GDP) of Canada, India and Mexico.⁴⁷ Most of the countries in our research have policies or programmes in place for control of exposure to environmental hazards, and air quality programmes may exist as distinct policies or be encompassed within climate and energy strategies. A specific air quality strategy exists in all our countries except Norway, which has an environmental strategy but not one specifically focused on air quality.

The patient is speaking, but is anyone listening?

The involvement of patient organisations in policy development can help to build consensus on many levels; they ensure the inclusion of patient needs and improve decision-making.⁴⁹ However, lung cancer specific patient organisations only exist in some of the countries covered in this report, and where they do exist there is significant variation in the roles they play in policy development.⁴⁹ In some cases they are nascent organisations that are not yet fully established, thus their role is minimal. In others, patient organisations are well networked and active participants that engage with government stakeholders to increase awareness and contribute to policy development.

Seven out of 11 countries have lung cancer specific patient organisations: France, the Netherlands, Norway, Poland, Spain, Sweden and the UK. Five countries have included patient organisations in the development of clinical guidelines: Belgium, France, the Netherlands, Sweden and the UK. Six countries include patient organisations in their health technology assessments (HTAs): Finland, France, the Netherlands, Poland, Romania and the UK. Including the patient voice provides insights into care and treatment from a perspective that is unique and impactful. We found that where patient organisations exist and play an active role, such as in Norway and Spain, participants valued their contributions; when they are missing, as in Austria, participants noted their absence.

Fresh thinking: opportunities for improvement

Will screening work for you? LCDT screening of high-risk populations shows potential to improve outcomes. However, screening in cancer is often controversial, and the most important factor is that it is informed by an evidence-based approach. All countries should investigate the potential impact of screening.

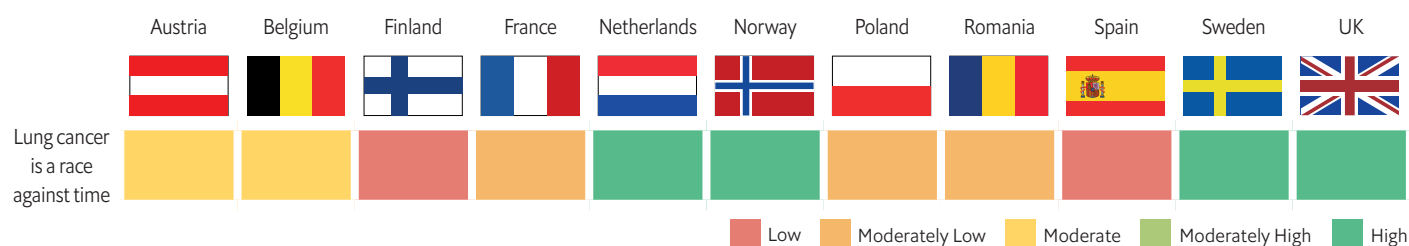
Smoking bans. The vast majority of lung cancer cases are caused by smoking. Although much headway has been made in banning or controlling smoking, more can be done in several countries

to ensure that offices, public transport and other places of social gathering remain smoke free.

Keep an eye on e-cigarettes. Another controversial area. The impact of long-term use is unknown, and there is concern that many vaping products are being purposely targeted at children and teens. The science and policy discussions around e-cigarettes will move fast, and it is the responsibility of policymakers to remain informed and evidence led.

Involve patients. The involvement of patients can help to improve guidelines and HTAs. Including patient experience provides insights into care and treatment from a perspective that is unique and impactful.

Lung cancer is a race against time



The race against time domain addresses issues around early diagnosis and referral to treatment. These need not only be discussed in guidelines, but specific referral pathways and timelines should be in place. Four countries performed well in this domain: the Netherlands, Norway, Sweden and the UK. The countries with the lowest performance were Finland and Spain. Austria and Belgium performed better than France, Poland and Romania. Note that although the indicators in this domain are based on policies and guidelines, many participants remarked that there can be a significant difference between what is on paper and the actual reality—including in high performing countries such as Sweden and the Netherlands.

Diagnosis needs to be fast-tracked...

Lung cancer is rarely diagnosed during the earliest stages of the disease, when curative treatment—most often surgery—is an option. Early, non-specific symptoms point to a variety of other diseases and conditions that are commonly found in primary care and so not necessarily at the front of a primary care practitioner’s mind. Diagnosis is therefore often delayed or missed altogether.^{50,51} Certainly, once a primary care physician suspects that a patient needs to undergo diagnostic testing, it is important that time is not wasted. Lung cancer clinical guidelines should include a fast-track for diagnostic testing. However, this is the case in only six of our countries: Austria, Belgium, the Netherlands, Norway, Sweden and the UK. And obtaining diagnostic testing within a specific timeframe is only discussed in the guidelines of five countries: Austria, the Netherlands, Norway, Sweden and the UK.

Participants stressed the importance of efficient and rapid diagnostic services for any patient suspected of having lung cancer. Some noted differences in the timing of initial suspicions of lung cancer in patients. These variations can be regional, not simply between nations. For example, in Sweden participants acknowledged regional variability both in the referral process and quality of care delivered—for instance, only about a third of patients receive treatment within the 40-day timeframe stated in the guidelines. It was said that in Austria a person suspected of having lung cancer could receive diagnostic testing within two days in Tyrol, compared with seven days in the capital, Vienna, and even longer in western Austria.

Even when guidelines cover diagnostic referral processes in detail, action on the ground is not always forthcoming. However, while we acknowledge that guidelines do not guarantee the delivery of the care described within their covers, they can establish national standards, hold providers to account and help to alleviate regional discrepancies.

...and the patient needs to be rapidly referred to specialised care

Once diagnosis has been achieved, the patient then must be rapidly referred into secondary and tertiary care. Delays are likely to worsen outcomes and can be psychologically stressful for patients. Research shows that delayed diagnosis increases mortality,⁵² but that the implementation of specific timeframes improves survival for lung cancer patients.⁵³ Providing a simplified fast-track referral pathway can improve the experience for both the lung cancer patient and primary care physician.⁵⁴ However, lung cancer clinical guidelines only mention such a pathway in four of our eleven countries: the Netherlands, Norway, Sweden and the UK.

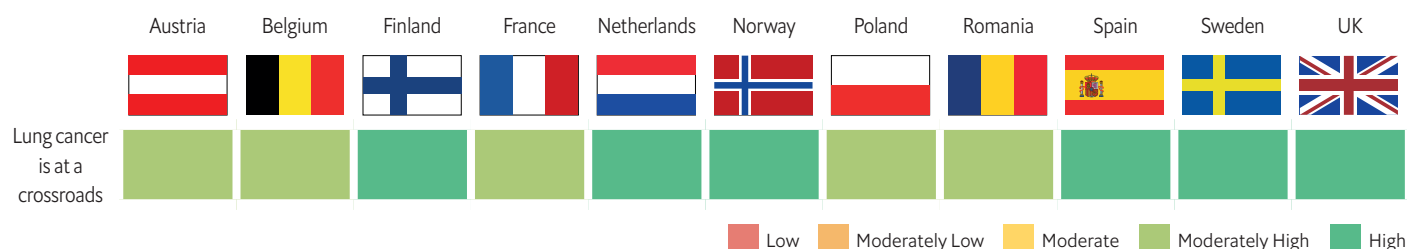
Another source of delay are the challenges that newly diagnosed patients may face in obtaining and coordinating appointments with multiple specialists. A multidisciplinary care system can alleviate some of these pressures: clinics organised around multidisciplinary care teams improve both time to diagnosis and initiation of treatment.⁵⁵

Fresh thinking: opportunities for improvement

Fast-tracking is essential and yet is often not discussed in guidelines. Clear fast-track referral pathways with timeline targets should be described. This applies both for diagnostic testing (when suspicions are first raised) and for referral to care teams once a positive diagnosis has been made.

Focus on hard-to-reach populations. Rapid diagnosis becomes a greater challenge for hard to reach populations, including disadvantaged and remote populations. Using technology effectively may improve the delivery of care to remote patients by allowing specialists to support the diagnostic efforts of local physicians (see next section).

Lung cancer is at a crossroads



The crossroads domain looks at treatment, from surgery through radiotherapy and chemotherapy, to newer targeted therapies and immunotherapy. It also covers supportive and palliative care and multidisciplinary teams. All countries performed relatively well in the scorecard, although there is plenty of nuance in this domain, and healthcare systems face challenges in ensuring that they deliver the best possible care. The best performing countries are Norway and Sweden followed by Finland, the Netherlands and the UK. The lowest performing country is Romania.

A new hope

With technology paving the way for earlier diagnosis and new treatments offering hope to patients, lung cancer care is at a crossroads.⁴⁶ The particular treatment that a lung cancer patient receives will typically be based upon the stage at which the diagnosis is made (taking into account other factors such as frailty and patient choice). Stages range from 0, a small, non-invasive tumour, to IV, the most advanced form of the disease, in which the cancer has spread to other parts of the body. Treatment can include surgery, chemotherapy, radiotherapy, targeted therapy and immunotherapy.

Table 3: Demand vs supply of radiotherapy megavoltage machines

	2012 MVM demand	2013 MVM supply	% of unmet need
Austria	70	47	-32.8%
Belgium	120	92	-23.3%
Finland	51	45	-11.8%
France	676	483	-28.6%
Netherlands	170	127	-25.3%
Norway	49	41	-16.3%
Poland	272	112	-58.8%
Romania	100	23	-77.0%
Spain	374	240	-35.8%
Sweden	89	76	-14.6%
United Kingdom	599	318	-46.9%

Source: Yap, et al. Global access to radiotherapy services: have we made progress during the past decade?, Journal of Global Oncology, 2016, 2(4):207-215.

The two common surgical procedures for lung cancer are lobectomy (the removal of an entire lung lobe) and wedge resection (removing only a portion of the lobe). Living without a lobe or even with only one lung is possible and does not usually impact life expectancy. Chemotherapy is drug treatment by agents that are systemic, not specific to a particular type of cancer: platinum-based chemotherapy is the recommended treatment for many lung cancer patients.⁵⁶ Radiotherapy uses radiation to kill cancer cells. We found significant variability in access to radiotherapy between countries. Most countries experience a demand for radiotherapy that exceeds the supply of radiologists and machinery to deliver the treatment (Table 3).^{57, 58} Variation in supply was also found within some countries. For example, participants reported that in the UK access to advanced radiotherapy techniques varies regionally.

Surgery, chemotherapy and radiotherapy have long been the backbone of cancer therapies. Over the past decade, however, new therapy options have emerged, including targeted therapy and immunotherapy. Targeted therapy consists of medications that specifically target certain cellular changes; because they are more focussed than systemic chemotherapy drugs, they often have less severe side effects. They are typically used for patients with advanced lung cancer either on their own or in combination with chemotherapy.⁵⁹

Immunotherapy leverages the body's own immune system to fight cancer.⁵⁹ The medication targets a protein receptor on a type of white blood cell called T-cells, also known as T-lymphocytes.⁶⁰ This process enables the T-cells to recognise cancer cells and kill them.⁶⁰ As with targeted therapy, it is possible to use immunotherapy alone or in combination with chemotherapy. In order to get an estimate of availability of targeted and immunotherapy drugs, we looked at the targeted therapies afatinib, crizotinib, erlotinib and gefitinib, and the immunotherapy drug pembrolizumab. Each was approved and reimbursed in our 11 countries.

Tumour testing: a necessary but often overlooked first step

The rise of targeted therapy and immunotherapy means that testing of tumours has become increasingly important. Testing to identify specific 'biomarkers' allows clinicians to identify which drug is the best match for the patient's cancer. There are four tests commonly used in lung cancer: anaplastic lymphoma kinase (ALK), epidermal growth factor receptor (EGFR), ROS proto-oncogene 1, receptor tyrosine kinase (ROS1) and programmed death ligand 1 (PD-L1). Choosing the right therapy for a specific patient increases the likelihood that he or she will respond to treatment.

Requirements for biomarker testing vary widely. In France, for example, over 90% of biomarker testing is done for first line immunotherapy treatment but this is not required for all second line immunotherapy treatments. The cost of biomarker testing is borne by the hospital from an annual budgetary allowance from the state; once that allowance has been depleted, the remaining costs of the tests must be funded from elsewhere in the hospital's budget. In other countries biomarker testing is not reimbursed at all by the public health system, or subject to an annual limit. This can result in situations where an (expensive) innovative treatment is reimbursed but the (inexpensive) diagnostic test is not. One way of avoiding this conundrum can be found in Belgium, where new legislation means that testing for some—though not all—biomarkers will be coupled with the treatment for reimbursement purposes.⁶¹

Biomarker testing is discussed in all 11 lung cancer clinical guidelines. However, only five countries reimburse all four biomarkers: the Netherlands, Norway, Spain, Sweden and the UK.

The shock of the new: systems are struggling with innovation

Access to new treatments can be a challenge for countries with limited resources. Attaining market approval is only the first hurdle: once approved, the country's health system must determine how it will be reimbursed. The delay between European Medicines Agency (EMA) approval and reimbursement was a concern for many of our participants. In Northern and Western European countries, the delay between market authorisation and patient access to new medicines can be anywhere from 100-200 days, whereas in Eastern and Southern European countries, the corresponding delay can be between 600-1,000 days.⁶²

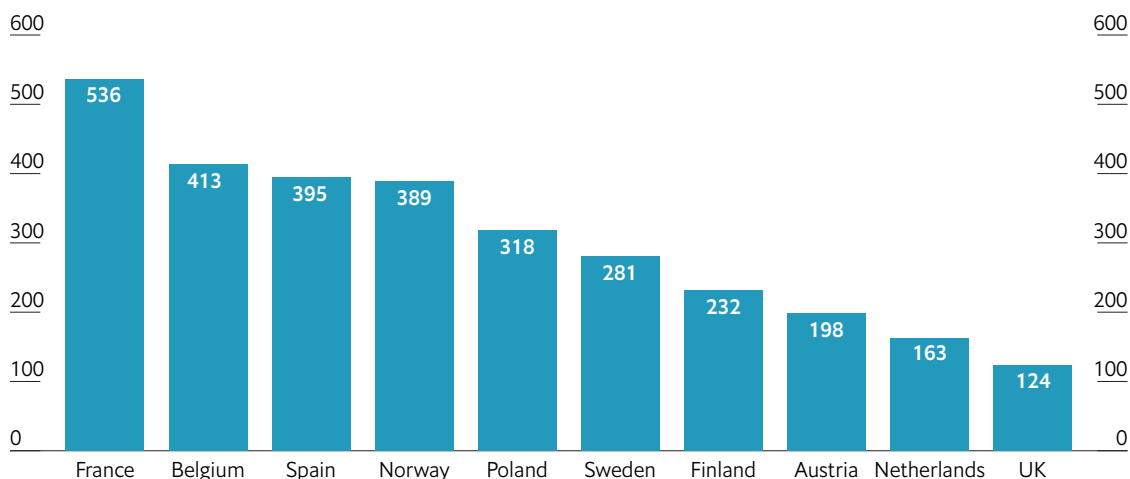
Reasons for these delays are varied, and some are more defensible than others. Delays may be due to pricing negotiations, deliberations during the HTA process, or because of decentralisation of decision-making to regional levels, as found in Spain or Sweden.¹² In Austria, access to newly approved medications can vary from 33 days to 1,383 days, depending on the region.⁶² Additional delays can also occur owing to lack of integration of the new treatments into clinical guidelines.¹²

The workshops allowed participants to discuss how their countries' health systems may be struggling to offer patients the best possible care—or in some cases, any treatment at all. Reasons for this are multifaceted. In the Netherlands, a lack of timely referral from primary to specialised care and insufficient knowledge about innovations in treatment were cited. In Finland and France, participants acknowledged the slow uptake of innovative treatments, while participants felt that Norway's medicines reimbursement agency was reluctant to engage with stakeholders.

In the short-term, earlier access to new treatments through clinical trials and compassionate use programmes can help to alleviate the situation. However, in the longer term, stakeholders need to

Figure 9: Length of average market access delays by country

(Average delay, days)



Note: No data available for Romania.

Source: IQVIA. EFPIA Patient W.A.I.T. Indicator 2018 Survey.

work together to ensure sustainable and equitable access. Critical to this is the inclusion of patient organisations to ensure that their voice is heard. However, five of the countries in our study do not include a patient perspective in HTA decision making: Austria, Belgium, Norway, Spain and Sweden.

The hub and spoke model can balance specialisation with localisation

Whether to provide access that is local to patients or centralised within fewer, major medical centres was a topic raised by many participants. Many countries face problems arising from inefficient care delivered via fragmented systems.¹² Certainly, centralisation of cancer services into specialised treatment hubs can help ensure that patients receive appropriate diagnostic and high-quality care. However, the relative lack of access for those living at a distance from the specialised hub becomes an issue—particularly in large and sparsely populated countries. Norway, for example, is exploring how diagnostic and surgical services could be centralised while using improved telecommunication services to decentralise treatment. This would allow patients to receive their treatment from locally based clinicians who can be in contact with the centralised hub specialists. France has a similar system of networks linking regional cancer facilities with designated centres of reference and centres of competence.¹²

Stigma is common, but support for mental health is not

Being given a lung cancer diagnosis causes immense distress to the patient and his or her family. Not only is it often considered a death sentence, patients also report a sense of stigma, associated with the disease's link to smoking.⁶³ Finnish smokers, for example, are often reluctant to bring themselves forward for screening because they feel the shame of a disease that they have brought upon themselves. Participants also spoke about the unconscious bias that some healthcare professionals have towards lung cancer patients and treating them for a self-inflicted disease. Psychological support—including problem-solving approaches, support group-based treatments and cognitive behavioural therapy—can help lung cancer patients and their families from diagnosis through treatment.⁶⁴

Too often, however, the psychological needs of cancer patients are not met. Many patients report wanting to obtain mental health support for their families but are unable to access it. Patients who have managed to get referred have reported being seen by professionals who either lacked a proper understanding of cancer or were unable to provide the help that they and their families needed. Some patients report that what help they did receive was inappropriate and hurtful.⁶⁵

Stigma has an impact beyond the emotional toll. For example, participants from the Netherlands discussed how both health professionals and patients may question the use of expensive treatments and whether the patient is deemed to be worthy of receiving it. Reducing negative attitudes and fatalistic thinking, while promoting anti-smoking efforts, has been shown to help to reduce stigma at a professional level and in society at large.^{18, 66} Indeed, participants from several countries—including Finland and Norway—reported that their health systems are looking for ways to confront the stigma and the barriers that it creates for people who are reluctant to take part in screening and early-detection services.

Psychological support services should be included in lung cancer clinical guidelines. However, this is only the case in six of our countries: Austria, Finland, France, the Netherlands, Norway and Sweden. Of these countries, only three—Austria, Norway and Sweden—provide clear referral pathways. Getting actual access to services remains an issue: for example, in the UK, psychological support is available at the time of diagnosis but support throughout treatment varies and is often a casualty of insufficient staffing.

Supportive and palliative care is often poorly organised and initiated too late

The WHO defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁶⁷ Sometimes the term “supportive” care is used for those services provided during the course of active treatment and “palliative” is reserved for end of life care. We treat supportive and palliative care as one continuum.

Research has shown that a country’s wealth does not always predict its ability to prioritise or organise supportive and palliative care.⁶⁸ Indeed, we found that access is often insufficient simply because a number of countries lack a suitable patient pathway. Despite supportive and palliative care being mentioned in clinical guidelines produced in nine of our eleven countries, specific referral pathways to these services are only provided in six countries: Finland, France, the Netherlands, Norway, Sweden and the UK. The lung cancer clinical guidelines used in Belgium and Romania did not discuss supportive and palliative care at all.

Multidisciplinary teams need to be co-ordinated

Table 4: Number of medical and surgical specialists (per 100,000)											
	Austria	Belgium	Finland	France	Netherlands	Norway	Poland	Romania	Spain	Sweden	United Kingdom
Thoracic surgeons	0.6	no data	2	0.7	0.9	1.0	1.4	1.6	1.7	1.4	1.5
General surgeons	22.1	11.5	8.7	7.6	9.7	8.6	15.5	12.8	11.4	16.1	13.4
Pulmonologists	4.8	4.7	3.7	4.7	5.1	3.7	4.2	5.7	5.5	2.1	4.1
Oncologists	no data	4	3.2	1.5	no data	4.2	5.7	3.1	3.9	5.7	3.8

Source: Eurostat. Data extracted May 2019.

Lung cancer treatment requires the services of oncologists, pulmonologists, thoracic surgeons, palliative care specialists and a host of nursing and allied health professional staff.²⁶ Provision varies extensively across countries (Table 4). The delivery of care is a complicated business, with many opportunities for co-ordination failure. Scarcity of specialist staff was reported by participants in several countries. For example, it was said that the UK suffers from significant shortages in pathology and radiology.

Multidisciplinary care teams are important to ensure the co-ordination of complex care requirements.⁶⁹ Ideally, these teams involve a mix of health professionals to ensure that the physical, emotional and psychological needs of patients are met. However, poor implementation can be due to limited resources, (competing) professional hierarchies and a lack of communication between team members.⁷⁰ Effective multidisciplinary teams tend to be organised around a regularly scheduled meeting where a range of patients are discussed.²⁶

Multidisciplinary care teams guide patient treatment in eight of our eleven countries. Austria, Finland and Spain do not include a discussion on the role of these teams in guidelines. Finally, training in supportive and palliative care for oncologists is available in seven of our 11 countries: Belgium, Finland, Norway, Poland, Spain, Sweden and the UK.

Fresh thinking: opportunities for improvement

Access to radiotherapy needs to improve.

All countries have more demand than supply. Although much talk in lung cancer care is about the potential of new drug therapies, radiotherapy remains the backbone of cancer treatment for most people. Investment in radiologists and radiotherapy equipment is needed.

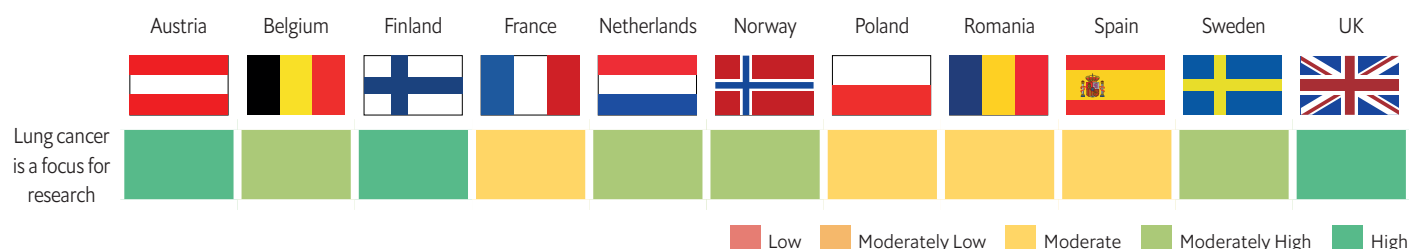
Access inconsistencies for biomarkers. Many European countries fund an expensive drug but not the inexpensive biomarker to identify when that drug would be useful. Access to biomarker testing is an important step to ensure that lung cancer patients receive appropriate treatment.

Be proactive in managing innovation. Access to new treatments can be a challenge even for

highly resourced countries. A balance needs to be achieved between sustainability and availability along with a public discussion on costs. Access to clinical studies and compassionate use can help to alleviate some of the pressure in the short term. In the longer term, it is important that stakeholders work together to ensure that medications are available in an equitable manner. This is likely to require innovative funding mechanisms, probably with some risk sharing.

Think beyond the tumour. Lung cancer takes a terrible toll on patients and their families. While there is often much anticipation about the arrival of a new medication or technology, patients and their loved ones will always need psychological, palliative and supportive care. Healthcare professionals should be trained to recognise this need, and clear referral pathways to specialist help should be provided.

Lung cancer is a focus for research



The research domain looks at research funding and the use of population registries. These registries can support a wide range of activities, one of which is the facilitation of high-quality research. Three countries performed well in this domain: Austria, Finland and the UK, followed by Belgium, the Netherlands, Norway and Sweden. The worst-performing country was Poland, followed by France, Romania and Spain.

Registries exist, but quality and coverage must improve

Population-based cancer registries collect and store data on patients diagnosed with cancer. They are a key resource for understanding cancer burden, prevention, treatment and outcomes, as well as providing insights into national cancer control programmes. The epidemiological data gathered assist in the evaluation of past performance and help plan for future needs.^{71, 72} However, previous research has suggested that registry coverage in some European countries has been below expectations, largely owing to concerns about data protection and consent.⁷³

Cancer registries exist in all 11 of our countries, but they vary in quality. Seven countries have high-quality national registries: Austria, Belgium, Finland, the Netherlands, Norway, Sweden and the UK. High-quality regional registries are found in France, Poland and Spain. Romania's registry was not found to be of high quality. Of the countries we studied, four have high-quality complete vital registration data (such as on births and deaths): Austria, Finland, Romania and the UK. Medium-quality vital registration was found in Belgium, France, the Netherlands, Norway, Spain and Sweden.

Many clinical participants reported that a clinically based cancer registry would provide helpful insights into the care they deliver to patients. Participants in the UK and France generally felt that systems were either in place or being built, whereas those from Austria, Finland and Spain wanted first to observe the French experience with that country's new system, the Health Data Hub which launches in autumn 2019. In Finland, participants wanted to ensure that any new system would make use of current technology so that physicians would not be overloaded with another set of forms to complete. Participants in Norway were also keen for change, and noted that their INSPIRE project, launched in 2019, aims to improve the quality of lung cancer data.

Health System Financing

Comparability issues arise when looking to understand potential associations between cancer outcomes and health systems between countries. Health spending varies according to national wealth, government involvement in health and social care, and variations in financing methods. The health systems in Austria, Belgium,

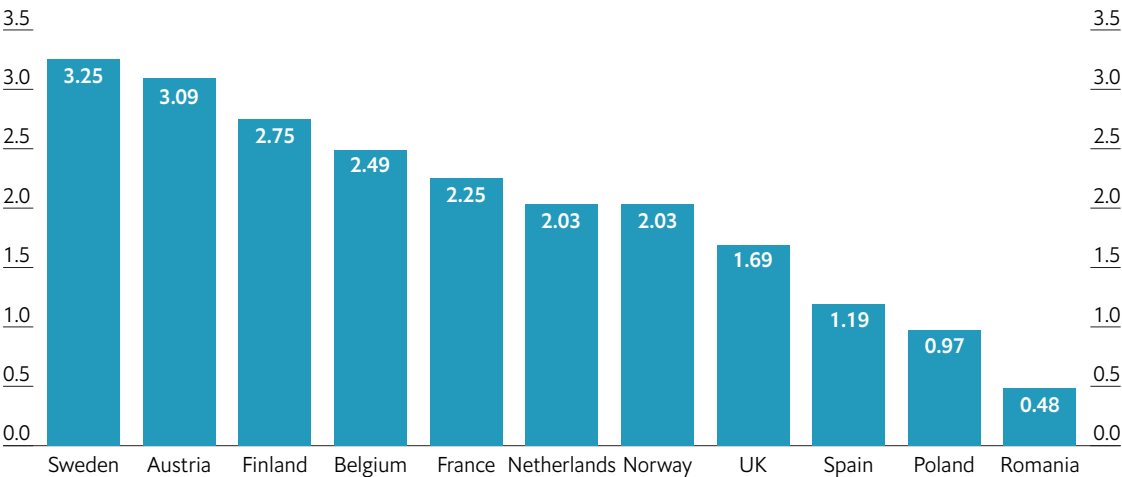
France, the Netherlands, Poland and Romania are funded by insurance. In contrast, those of Finland, Norway, Spain, Sweden and the UK are tax based.⁷⁴ Evidence suggests that national health systems have more control over expenditure, more equitable distribution of resources and lower out of pocket expenses compared with social insurance systems. However, cancer survival appears to be similar regardless of financing method.⁷⁴

Lung cancer has been under-researched

Given the burden of the condition, it has been argued that lung cancer has historically been under-researched when compared to other cancers.⁷⁵ Despite causing 20% of cancer mortality, lung cancer receives only 5.6% of all cancer research funding.⁷⁶ Improvements in public engagement and advocacy may help to address this anomaly.⁷⁷

Obtaining reliable, comparable research spend on lung cancer specifically—or indeed cancer in general—is challenging. To gain an understanding of how research is prioritised across included countries, we looked at the percentage of GDP used to fund R&D in general (i.e. not just pharmaceutical or clinical research). The rates varied widely in our 11 countries: Romania, Poland and Spain invest the least into research; Sweden, Austria and Finland the most (Figure 10).

Figure 10: R&D spending
(% of GDP)



Source: World Bank, 2019.

Fresh thinking: opportunities for improvement

Improve cancer registries. Cancer registries should not just hold data on incidence and stage at diagnosis, but also treatment received and outcomes. There are examples of good practice: the National Lung Cancer Audit in England and Wales satisfies the need for clinically focused care, and in France the Health Data Hub will encompass a clinical registry as well as information

on treatment and reimbursement. In Norway, the INSPIRE project was launched to improve the quality of lung cancer data. These approaches hold lessons for other countries looking to improve the quality of the data collected.

Is lung cancer receiving sufficient attention?

Although there is always competition for funding, lung cancer has long been under-addressed. This may partly be due to unconscious stigma at both an individual and institutional level. Is lung cancer sufficiently prioritised in your country?

Conclusions and a call to action

This report documents the findings of the first phase of our research into European lung cancer policy, covering findings from 11 countries. Separate country profiles for each country dive into national findings and opportunities for improvement. In early 2020, we will publish the findings for a further 16 European countries. Already, however, interesting regional themes have emerged. Opportunities exist across the board, and there is no country or domain with high scores across each of the indicators that we measured. Even where individual countries may have received a high domain score, there are often opportunities for further improvement or nuances behind the scores that may not have been captured by our indicators.

It is worth reflecting on the limitations of the study. The use of policy scorecards inevitably involves collapsing complex, on-the-ground situations into simple scores. Much information is lost during the transformation and people will inevitably quibble over the scores. We have tried to remain as transparent as possible, offering the rationale for scores and providing references where possible.

Another limitation is that one cannot measure everything in a scorecard. We followed an evidence-based process, including the use of an advisory board, to identify key domains and informative indicators. However, topics inevitably came up during the workshops that we had not measured or had measured but in a way that perhaps did not capture every side of the story. We have tried to discuss such matters in this report and added detail in the opportunities for improvement sections of the country profiles. The advantage of using scorecards is that they offer a snapshot comparison of strengths and weaknesses and can be a route into a wider discussion of what countries can do to improve processes and offer better outcomes to patients.

Our findings—from both secondary and primary research—show that lung cancer must be shunted to the top of the agenda. New and improved diagnostic, screening and treatment options are becoming available that will help patients live longer and with a better quality of life, and decisions need to be made about how these opportunities will be incorporated into current care pathways. In addition, policies on awareness, prevention and health literacy can be strengthened. There really is no reason why lung cancer should remain the most lethal cancer in Europe.

What needs to be done? Building partnerships and collaboration between national stakeholders will promote meaningful dialogue and policy development. These include forging alliances between ministries of health and public health, finance, social services and education; healthcare providers; patient organisations; and industry. Although there has been a gap between political ambition and clinical reality in the past, this gap can close. And with it needs to be the removal of stigma, which still plagues lung cancer, in the same way that stigma hung around all cancers a few decades ago. As one workshop participant succinctly put it, “anyone with a lung can get lung cancer”.

The key action points are:

An improvement in strategic planning and the means to collect data to inform it

National Cancer Control Plans and, ideally, a specific lung cancer control plan, should be in place, regularly updated and properly funded. In the same way that cancer control plans can go into greater detail than a general non-communicable disease (NCD) plan about the unique challenges of (and solutions for) cancer, so lung cancer control plans are able to really focus on matters of importance for improving the lives of lung cancer patients. They should be revised every five years to ensure that they encompass the latest developments, and to be of any use they need to identify specific funding sources. As a speaker during a recent political event in Norway stated, “a plan without a budget is a vague idea.”

These national plans should become a meaningful part of how a country looks to improve both the efficiency and effectiveness of care, as well as reducing the number of people who need care in the first place. Although a plan does not guarantee action—as many of our participants noted—without a plan, little co-ordinated action is likely to happen at all. Countries with devolved health systems need to find workable solutions to ensure that their National Cancer Control Plan can be adopted to ensure equitable care across every region in a country. To address the challenge of low health literacy throughout Europe, health literacy strategies should be included in national plans.

Finally, one of the most important markers of a cancer care plan is that it includes an implementation and evaluation plan. And to evaluate the impact of a plan, data is required. All countries had some form of registry, but most participants acknowledged weakness either in geographic or clinical coverage. Registries—and the real-world data that they collect—offer so much value to so many stakeholders that it is short-sighted not to invest in them. To maximise their value, registry data, generally anonymised, should also be available to those outside the healthcare system—whether freely distributed or sold on the market.

A renewed focus on early detection, including an assessment of the pros and cons of a national screening programme

Lung cancer clinical guidelines should of course encompass all aspects of care through clear pathways and quality indicators. Timeframes should also be embedded within the guidelines, as they serve as critical benchmarks to evaluate performance. This is of the essence for lung cancer patients, where late diagnosis is rife. Awareness needs to be improved throughout the primary care system to ensure that high-risk patients are identified and obtain the necessary screening to ensure that the disease is identified as early as possible.

Published evidence suggests that opportunities to maximise early diagnosis can be improved with the use of diagnostic assessment clinics. These are locations where diagnostic testing and multidisciplinary care can be provided in one place.^{28, 78}

Pharmacists can also help in identifying patients for assessment. A lingering cough can be symptomatic of many things, but pharmacists may see someone repeatedly purchasing items such as cough medicine.²⁸ If the pharmacist is suitably trained and aware, this can offer an opportunity to have a discussion with the person or alert the primary care team.

Finally, we argue that LDCT screening programmes of high-risk populations should be considered. We recognise that the challenges of implementing, funding and evaluating such programmes are substantial. For example, the healthcare system would need to be able to manage the increased number of patients diagnosed, and the screening programme would need to be supported by primary care providers, although their current risk-assessment capabilities may often be lacking.⁷⁹ The increased awareness and availability of screening services among the public and among primary care personnel may help to address unmet needs in the early detection of lung cancer.⁸⁰ We do not recommend a yay or nay, we merely urge an evidence-based approach to informing the decision on whether or not to implement LDCT screening programmes.

Put patients front and centre, and ensure that they are heard by decision makers

Improvements are needed in all aspects of a lung cancer patient's journey from the first suspicion of disease and screening through diagnosis and treatment. Healthcare systems can take the first steps to address this by improving awareness of lung cancer and its tribulations among both the general population and primary care health professionals. Understanding is a first step towards changing behaviour.

Raising awareness can also be of practical help. The wide range of symptoms associated with lung cancer mean that it is difficult to identify from early symptoms alone; clearly, communicating risk factors can help to empower patients to ask their primary care physicians whether they should seek screening. Relatively simple changes to care delivery can make a big difference. For example, running a lung clinic can improve patient experience immensely by reducing stigma of attendance and improving the co-ordination between the array of specialists that patients need to see.

Policymakers and system administrators also need to ensure that there are processes through which the patient voice can be heard. The involvement of patient organisations in national assessments of disease and policy development can help to build consensus. Occasionally such organisations are disruptive too—but they tend to wield the creative disruption that healthcare systems need to go through to move towards genuinely patient-centred care.

Create systems to ensure sustainable and equitable access to innovations

Recent medical innovations and technological developments have improved diagnostic and treatment options for lung cancer patients. For people with the disease there are opportunities for improved quality of life and longer survival. However, much of the new technology is expensive, and improved and sustainable funding solutions need to be found to ensure that high-quality care is available for patients. We described it as the “shock of the new”, and as with any paradigm shift, there is a period of transition as systems and structures struggle to re-orient themselves.

Ensuring access to biomarker testing and enabling patients to obtain improved access to innovative therapies is one step. Certainly, meeting the costs of expensive medications while not reimbursing for the (relatively) less expensive biomarker tests seems counterproductive. More generally, it is not necessarily a case of just spending more money, as there is not always more money to spend. But participants in our workshops were very keen that key players, including manufacturers, policymakers and HTA organisations, worked together to find regulatory and reimbursement models that share risk and help to get innovations to patients more quickly. Access is a whole other topic area—one that is beyond the scope of this report—but one thing is certain: delays between marketing authorisation and availability to patients have a very real impact on today's patients and their families.

De-stigmatise the disease through education, awareness and compassion

Stigma remains an issue. Patients with lung cancer often get the feeling that whoever they speak to is thinking the same thing: that in some way, as the patient, it is their fault. Sometimes, patients agree with this assessment, and so do not feel worthy of receiving high-quality and possibly expensive care. This delays diagnosis and leads to unnecessary suffering.

Reducing negative attitudes and fatalistic thinking, while promoting anti-smoking efforts, can help to reduce stigma at both a professional level and in society at large.^{18, 66} It is encouraging that several countries covered in this research appear to be looking into how stigma and its associated barriers to good care can be reduced.

Finding solutions to address stigma and ensuring that patients receive the psychological, supportive and palliative care that they need, is vitally important. Certainly, other diseases have faced or continue to face negative stigmas, and the strategies used in those cases may be adapted for use in lung cancer. It is time that all people with lung cancer are treated with compassion and dignity.

Appendices

Methods

Our research is in two phases. This document covers the first phase of our research, in which we analyse the 11 countries: Austria, Belgium, Finland, France, the Netherlands, Norway, Poland, Romania, Spain, Sweden and the United Kingdom. Germany and Greece were originally part of this phase but due to workshop scheduling reasons, they will be included in the second phase of our study along with an additional 14 countries which will be published in early 2020. Upon completion of phase 2, we will have analysed 26 European countries plus Israel. Countries in phase 1 are all either upper-middle or high income economies.

At the heart of the research project is a benchmarking exercise of scoring policies, programmes, guidelines and approaches for patient-centred care. Its goal was to spur debate around the need for a transformative change in lung cancer screening, diagnosis, treatment and supportive and palliative care. An initial literature review, conducted via Embase.com, identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. Search results were limited to reviews and systematic reviews published in the last five years. The 379 retrieved articles were first sifted based on title and abstract, followed by full text appraisal.

From analysis of the most relevant articles identified, we derived a draft set of indicators with which to benchmark policy and systems in European countries. The goal is to identify those policy and system “building blocks” that are associated with high-quality care and good patient outcomes. These form the basis of the indicators, which are clustered into domains.

An editorial advisory board was convened to review and advise on the development of the indicator framework and the organising domains. Out of this process, we identified a set of 17 indicators to evaluate each selected country across five domains. We created scoring schema, then researched, assessed and scored countries. A range of international and national sources were used for the data collection, and both primary and secondary research used to populate the country scorecard.

Scoring judgements were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, we attended workshops in each country with external country-based experts, hosted by the sponsor, to discuss the scores and help us to develop recommendations. The EIU retained editorial independence throughout the process.

The scorecard

Domain	Number	Indicator	Source	Scoring criteria
Lung cancer is a strategic priority	1	A comprehensive, up to date national cancer control plan is in operation	Cancer Atlas/ WHO / Individual country documents	1 = operational national cancer control plan exists 1 = cancer control plan was updated within the last 5 years 1 = cancer control plan includes implementation plan 1 = cancer control plan identifies funding source 1 = lung cancer specific control plan exists
	2	Comprehensive, clinical guidelines for lung cancer exist	Individual country documents	1 = lung cancer clinical guidelines exist* 1 = guidelines cover screening for lung cancer 1 = guidelines cover diagnosis for lung cancer 1 = guidelines cover treatment for lung cancer 1 = guidelines cover supportive/palliative care for lung cancer 1 = guidelines cover shared decision making for patients with lung cancer <i>* one point for guidelines will be given whether the country has developed their own guidelines or if they have adopted international guidelines</i>
Lung cancer is a public health issue	3	Tobacco control policies and public health measures are in place	WHO / UN	1 = government objectives on tobacco control exist 1 = national agency for tobacco control exists 1 = advertising tobacco on national TV and radio is banned 1 = at least one national anti-tobacco mass media campaign has been aired between 2014 and 2016 1 = law mandates that health warnings appear on tobacco packages 1 = country is a party to the WHO Framework Convention on Tobacco Control 1 x 3 = national smoke-free legislation exists for indoor offices, restaurants/cafes/pubs/bars, and public transport
	4	E-cigarettes are regulated and covered by public health measures	Individual country documents	1 = regulation for e-cigarettes exists 1 = e-cigarette sales subject to an age limit 1 = e-cigarette advertising is banned 1 = e-cigarettes are banned in public areas (e.g. public transport, civic buildings, restaurants, cafes, pubs and/or bars)
	5	National policies and programmes to control environmental exposure exist	Individual country documents / WHO	1 = an air quality strategy exists 1 = a national radon control programme / policy exists
	6	An evidence-based approach to lung cancer screening has been followed	Scientific literature	1 = a study has been / is currently being conducted in this country and / or a trial screening programme is in place (demonstration/pilot)
	7	Patient organisations have a voice in policy development	Individual country documents / WHO	1 = one or more independent lung cancer patient organisations exist 1 = one or more independent lung cancer patient organisations are listed as contributors in clinical guideline 1 = civil society has the opportunity to comment on HTA recommendations
Lung cancer is race against time	8	Suspected lung cancer patients are diagnosed within a specific timeframe	Individual country documents	1 = guidelines mention suspected lung cancer patients are to be fast tracked to diagnosis 1 = guidelines mention a specific timeframe for diagnostic referral in suspected lung cancer patients
	9	A pathway for rapid referral to quality care exists	Individual country documents	1 = national guidelines / pathways for rapid referral for lung cancer patients are in place 1 = guidelines recommend that patients are treated by a multidisciplinary team

BREATHING IN A NEW ERA

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Domain	Number	Indicator	Source	Scoring criteria
Lung cancer is at a crossroads	10	Access to medical and surgical specialists	Scientific literature / Individual country documents	number of (per 100,000) pulmonologists thoracic surgeons general surgeons oncologists unscored
	11	Radiotherapy is accessible	Scientific literature	unscored
	12	Tumour testing is recommended and accessible	Individual country documents	1 = biomarker testing is mentioned in guidelines or pathways for lung cancer 1 = specific markers are identified in guidelines or pathways for lung cancer 1 x 4 = tests (EGFR, ALK, ROS1 and PD-L1) are reimbursed under national public health system
	13	Key targeted medicines are accessible and reimbursed	Individual country documents	1 x 5 = approved but not reimbursed 1 x 5 = approved and reimbursed erlotinib, gefitinib, afatinib, crizotinib, pembrolizumab each drug will be scored
	14	Psychological burden of lung cancer is understood and support services are in place	Individual country documents	1 = guidelines mention psychological burden of lung cancer 1 = guidelines include a referral pathway to psychological support services for lung cancer patients
	15	Patients have access to supportive / palliative care services	Individual country documents	1 = guidelines include referral pathway to supportive / palliative care services for lung cancer patients 1 = oncologists receive training in supportive / palliative care
Lung cancer is a focus for research	16	Clinical and outcomes data is collected	Cancer Atlas / Individual country documents	Population-based cancer registry 0 = no data/status unknown 1 = PBCR (national or regional) 2 = high quality PBCR (regional) 3 = high quality PBCR (national) Vital registration data 0 = no data/status unknown 1 = incomplete or sample vital registration 2 = low quality complete vital registration 3 = medium quality complete vital registration 4 = high quality complete vital registration
	17	Research is supported and funded	World Bank	unscored

Workshop participants

We thank the following experts—from various fields of study and points of view—who kindly contributed to the research by sharing their knowledge and experience. These country workshop participants consented to their names, job titles and organisations being included in the final report, as a confirmation of their participation.

It is important to note that the participants listed here have not seen the final report before publication and had no input to it (beyond their contribution to a workshop). Therefore, inclusion on this list is no endorsement of the support for this report or its conclusions.

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Lung cancer: a patient's view

We thank one of our patient representatives, André Stoop, for these few words on what a diagnosis of lung cancer means.

The riskiest adventure of my life

I am a very active sportsman, a smoker always.
As a scientist, I know the dangers of tobacco.
But the post-exercise cigarette is a great reward.
And it gives you plenty of confidence.
The cancer is not for me, I walk on him, I crush him...
...why is this pain between my neck and shoulder?
Months and months of throbbing, abdominal pains.
A few key words in MEDLINE & EXCERPTA MEDICA.
An article describes my symptoms. It is not possible anyway!
A worried sports doctor requests a test.
Diagnosis: lung cancer. Survival rate almost zero.
Extensive treatment, drugs, drugs, again and again, treatments, treatments and more treatments.
Weight in free fall. When will it stop?
Pain and more pain, thrombosis and other delights.
Already 15 years ago, but never forgotten, never, never.

Please listen to them.

Do not do as I did: do not wait to prove it to yourselves by trying this mega-risky experience: smoking cigarettes and ignoring that the tobacco in it leads you straight to death row.

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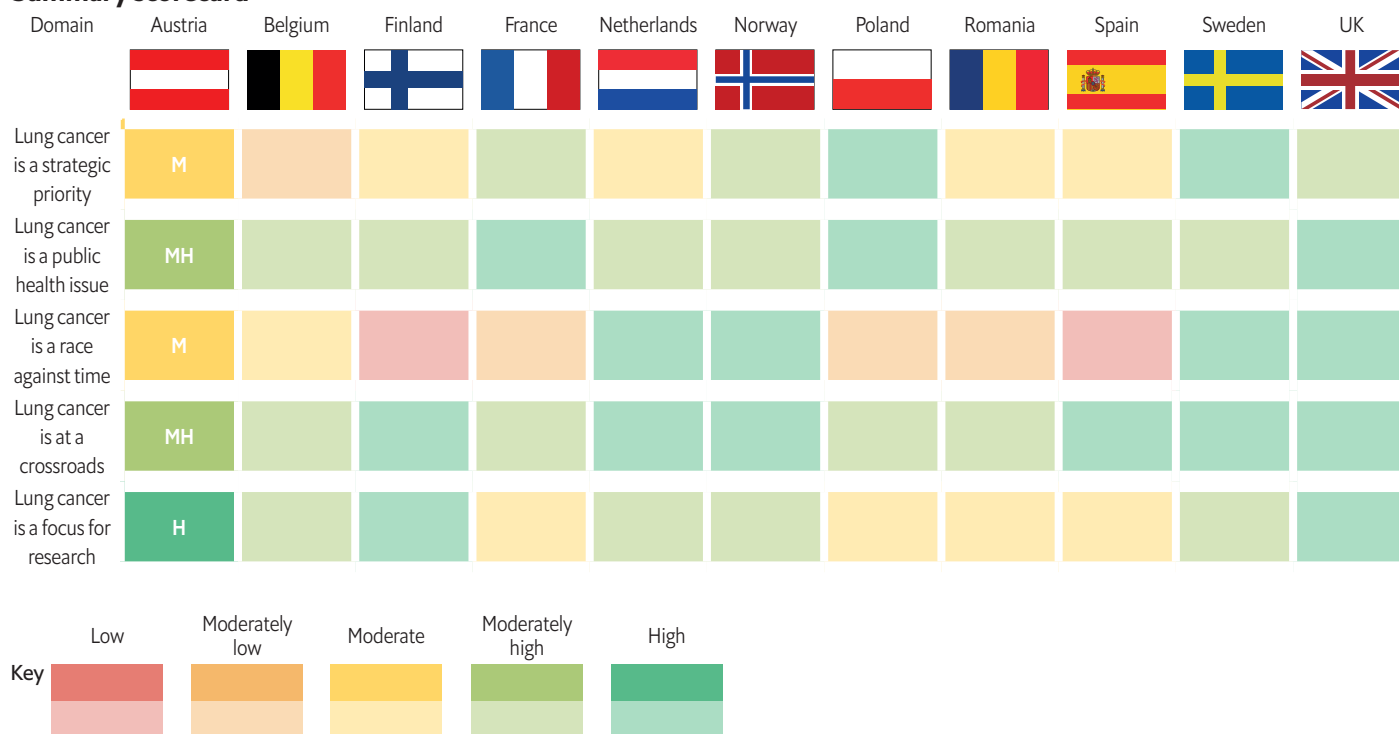


Austria: Lung Cancer Country Profile

Austria performs moderately well across all five domains, scoring 'high' in the R&D domain, 'moderately high' in the public health and treatment domains, and 'moderate' in the strategic and rapid referral domains. The merely moderate performance in the first domain results from the need for a lung cancer specific control plan, an updated National Cancer Control Plan which includes an implementation schedule and a funding source, and a discussion of screening in the guidelines. Scores in the third domain, on referral, would improve if the guidelines included discussion of multidisciplinary care teams and a rapid referral pathway to secondary and tertiary care. Including a referral pathway to supportive and palliative care in the guidelines would improve performance in the fourth domain along with reimbursement of biomarker testing. We discuss opportunities for improvement at the end of this country profile.

The costs to Austrian society from tobacco have not been fully addressed and achieving national smoke-free legislation has been a challenge. However, in July 2019, the government passed a ban on smoking in restaurants and bars which is to go into effect on 1 November 2019. Workshop participants noted the challenge of identifying the point at which clinicians begin to suspect a patient of possibly having lung cancer. Identifying patients as early as possible is key to improving outcomes. In terms of lung cancer clinical guidelines, there are two sets used: (1) the Austrian Cancer Aid and Austrian Society of Pulmonology lung cancer guidelines and (2) the German Society of Pneumology and Respiratory Medicine guidelines.

Summary scorecard



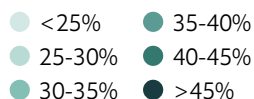
Sponsored by



Austria

Lung cancer incidence

(Rate per 100,000, 2017)



Austria

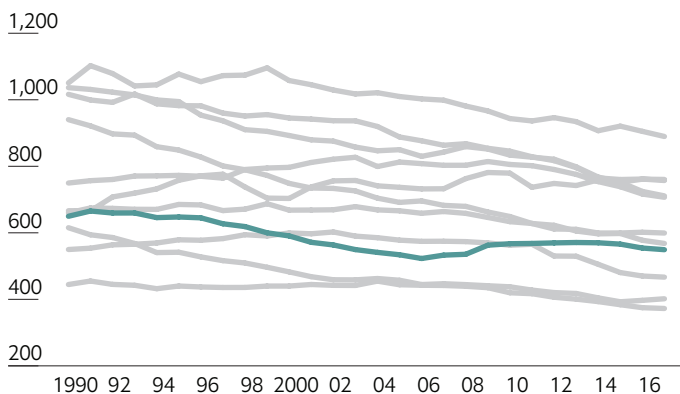
Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Austria	Europe	Global
Incidence	33	33	27
Prevalence	67	54	41
Mortality	24	27	24
Disability-Adjusted Life Years (DALYs)	549	628	503
Years Lived with Disability (YLDs)	9	8	7
Years of Life Lost (YLLs)	540	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

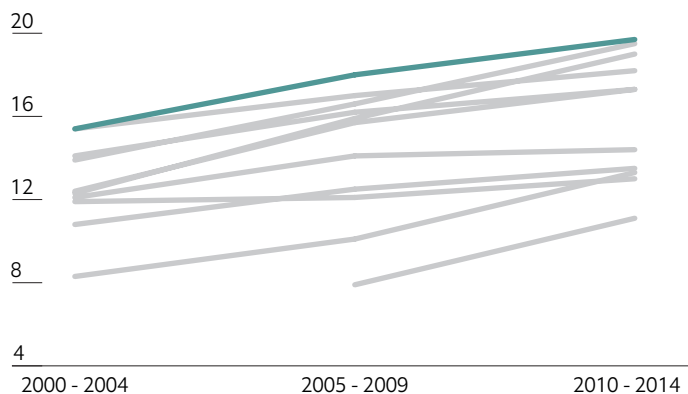
The costs of tobacco

Tobacco costs the economy €6,748 million in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 10,100 deaths in Austria.²

Survival trend

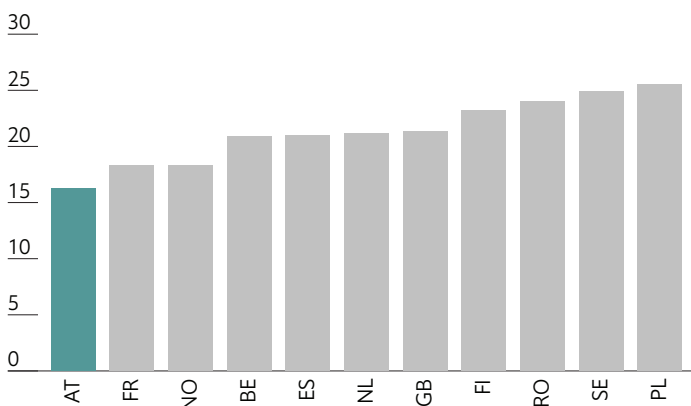
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

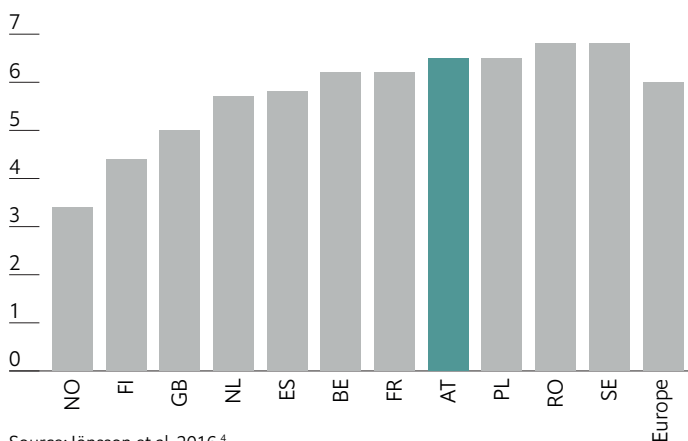
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator		Range	Score	Justification
Lung cancer is a strategic priority				
1	Operational, comprehensive, up to date national cancer control plan	0 – 5	1	<ul style="list-style-type: none"> ● An operational National Cancer Control Plan was published by the Federal Ministry of Health in 2014.⁷ ● There is no mention of an implementation plan or a funding source. ● A specific lung cancer control plan has neither been published nor discussed by the government or health ministry.
2	Comprehensive clinical guidelines for lung cancer	0 – 6	5	<ul style="list-style-type: none"> ● The Austrian Cancer Aid and Austrian Society of Pulmonology published lung cancer guidelines in 2017.⁸ Austria has also adopted the guidelines that were authored by the German Society of Pneumology and Respiratory Medicine that were published in 2018.⁹ ● Guidelines mention diagnosis, treatment and supportive / palliative care. ● Shared decision making is not covered in the guidelines published by the Austrian Society of Pulmonology but it is covered in the guidelines published by the German Society. ● Guidelines do not mention screening.
Lung cancer is a public health issue				
3	Tobacco control policies and public health measures	0 – 9	7	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.¹⁰ ● Austria is party to WHO's Framework Convention on Tobacco Control (FCTC). ● At least one national mass media campaign ran during the survey period (up to 2016). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● In July 2019, Austria voted to ban smoking inside bars and restaurants: the law is to be effective from 1 November 2019. ● National smoke-free legislation does not exist for indoor offices or public transportation.
4	E-cigarettes regulation and public health measures	0 – 4	4	<ul style="list-style-type: none"> ● Safety, quality standards and regulation are in place for e-cigarettes. ● As of 1 January 2019, sales of e-cigarettes are prohibited to people under 18 years of age. ● There are provisions that restrict the use of the packaging for advertisement or promotional purposes, as well as advertising, promotion and sponsorship in print and media. ● E-cigarettes are banned in public places where tobacco is prohibited and in private vehicles when someone under 18 is present.
5	National policies and programmes for environmental exposure control	0 – 2	2	<ul style="list-style-type: none"> ● Austria has a Climate and Energy Strategy that was implemented in 2018. ● WHO states that Austria has a radon control programme.
6	Evidence-based approach to lung cancer screening	0 – 1	0	<ul style="list-style-type: none"> ● No data found to show that Austria has conducted a lung cancer screening study or trial.
7	Patient organisations involvement in policy development	0 – 3	0	<ul style="list-style-type: none"> ● A specific lung cancer patient organisation has not been identified in Austria. ● There is no clear evidence to suggest that patients were represented in clinical guideline development. ● Patient organisations are not involved in Health Technology Assessment (HTA)
Lung cancer is a race against time				
8	Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	2	<ul style="list-style-type: none"> ● Fast tracking is not covered in the guidelines published by the Austrian Society of Pulmonology but it is covered in the guidelines published by the German Society. ● The Austrian guidelines do not mention a specific timeframe for diagnostic referral in suspected lung cancer patients but the German Society's guidelines state that the aim to diagnose lung cancer within 2 months.

Indicator	Range	Score	Justification
9 Guidelines/ pathways for rapid referral to quality care	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not mention rapid referral for lung cancer patients to secondary or tertiary care. ● The Austrian lung cancer guidelines do not mention referral to a multidisciplinary team to guide treatment plans. The German guidelines recommend multidisciplinary teams however it is unclear whether they are recommended to guide treatment plans.
Lung cancer is at a crossroads			
10 Medical and surgical specialists	number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2015: 4.83 pulmonologists 0.56 thoracic surgeons 22.09 general surgeons No data on number of oncologists.¹¹
11 Radiotherapy accessibility	unmet need	unscored	<ul style="list-style-type: none"> ● -23 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -32.8%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	2	<ul style="list-style-type: none"> ● Austrian guidelines recommend reflex testing for EGFR mutations and ALK and ROS1 rearrangement in (a) all adenocarcinomas, (b) NOS carcinomas (TTF1-, p40-), and (c) carcinomas with adenocarcinoma components (TTF1+). ● Specific markers are identified: EGFR, ALK and ROS1. ● No data identified on whether the tests are reimbursed: public or private.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines include psychological assessment and mention the psychological burden of lung cancer but state that not all patients may require it. ● Austrian lung cancer guidelines do not mention a referral pathway to psychological support services however the German lung cancer guidelines state that there are routinely used screening instruments that specialists use when investigating whether patients need psycho-oncological help.
15 Patient access to supportive / palliative care services	0 – 2	1	<ul style="list-style-type: none"> ● The Austrian lung cancer guidelines do not mention a referral pathway to palliative care. The German guidelines cover palliative care for lung cancer patients ● Austria has plans to adopt ESMO curriculum but there is no evidence to demonstrate that they have.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	7	<ul style="list-style-type: none"> ● High quality PBCR (national) (3 points out of a possible 3).¹² ● High quality complete vital registration (4 points out of a possible 4).¹²
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 3.09% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 168.¹³ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.39.¹⁴

Opportunities for Improvement

Opportunity 1

Recommendation

- Austria needs an updated National Cancer Control Plan.

Rationale

- *Indicator 1: Austria's National Cancer Control Plan was published in 2014 and needs to be updated. An updated national cancer control plan should ideally include the following elements—which were only weakly covered in the current plan: discussion of prevention, screening and early detection, red flags and symptoms to look for in primary care, diagnosis, an implementation plan and a funding source.*

Opportunity 2

Recommendation

- Achieving national smoke-free legislation in Austria has been a challenge. While legislation is now moving through the system, smoke-free legislation should be strengthened further.

Rationale

- *Indicator 3: The costs to Austrian society from tobacco have not been fully addressed. Smoke-free legislation was scheduled to go into effect in restaurants and bars in May 2018 but was then overturned by the government. A new law was passed in July 2019, which is now scheduled to go into effect on 1 November 2019. National smoke-free legislation in Austria should be strengthened by including a ban on smoking in indoor offices and on public transportation.*

Opportunity 3

Recommendation

- Participation in lung cancer screening trials and studies may enable Austria to determine whether screening is appropriate for its population.

Rationale

- *Indicator 6: There is no evidence to show that Austria has participated in a lung cancer screening study or clinical trial.*

Opportunity 4

Recommendation

- Involvement of patient organisations in national assessments of disease and policy development can help to build consensus.

Rationale

- *Indicator 7: A specific lung cancer patient organisation has not been identified in Austria, and there is no evidence that patients were represented in clinical guideline development. Involving patients in the development of clinical guidelines can 1) help to identify issues that may be overlooked by health professionals, 2) influence the development of recommendations from a patient and carer perspective, and 3) emphasise the importance of including shared decision making. Workshop participants felt that involving patient organisations would help them to understand if they were supporting their patients sufficiently.*

Opportunity 5

Recommendation

- Rapid referral for lung cancer patients to secondary and tertiary care should be prioritised within a specified time period as there is currently no mention of this in the clinical guidelines.

Rationale

- *Indicator 9: Providing timeframes within which lung cancer patients receive secondary or tertiary care provide important milestones for delivery of care. A rapid referral process for moving a patient to secondary or tertiary care is not discussed in either of the clinical guidelines that are used in Austria. It would benefit lung cancer patients to have pathways and specific timeframes set in the national lung cancer guidelines.*

Opportunity 6

Recommendation

- Lung cancer guidelines should include a referral pathway for supportive and palliative care. Also, there is no evidence that oncologists have received training in supportive or palliative care. Training should be included in the oncology curriculum.

Rationale

- *Indicator 15: While the German lung cancer guidelines discuss palliative care, the Austrian guidelines do not mention a referral pathway for supportive or palliative care. Similarly, there is currently no systematic training for Austrian oncologists in the area of supportive or palliative care. Austria is planning to adopt the ESMO curriculum but there is no evidence to show that they have done so, nor have they identified a date by which they plan to do so.*

Opportunity 7

Recommendation

- Cancer registries lack clinical data. In Austria, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Austria's cancer registry and vital registration data collection systems have been evaluated as being of high quality. Clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. Workshop participants felt that clinicians in Austria would benefit from such an improvement.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

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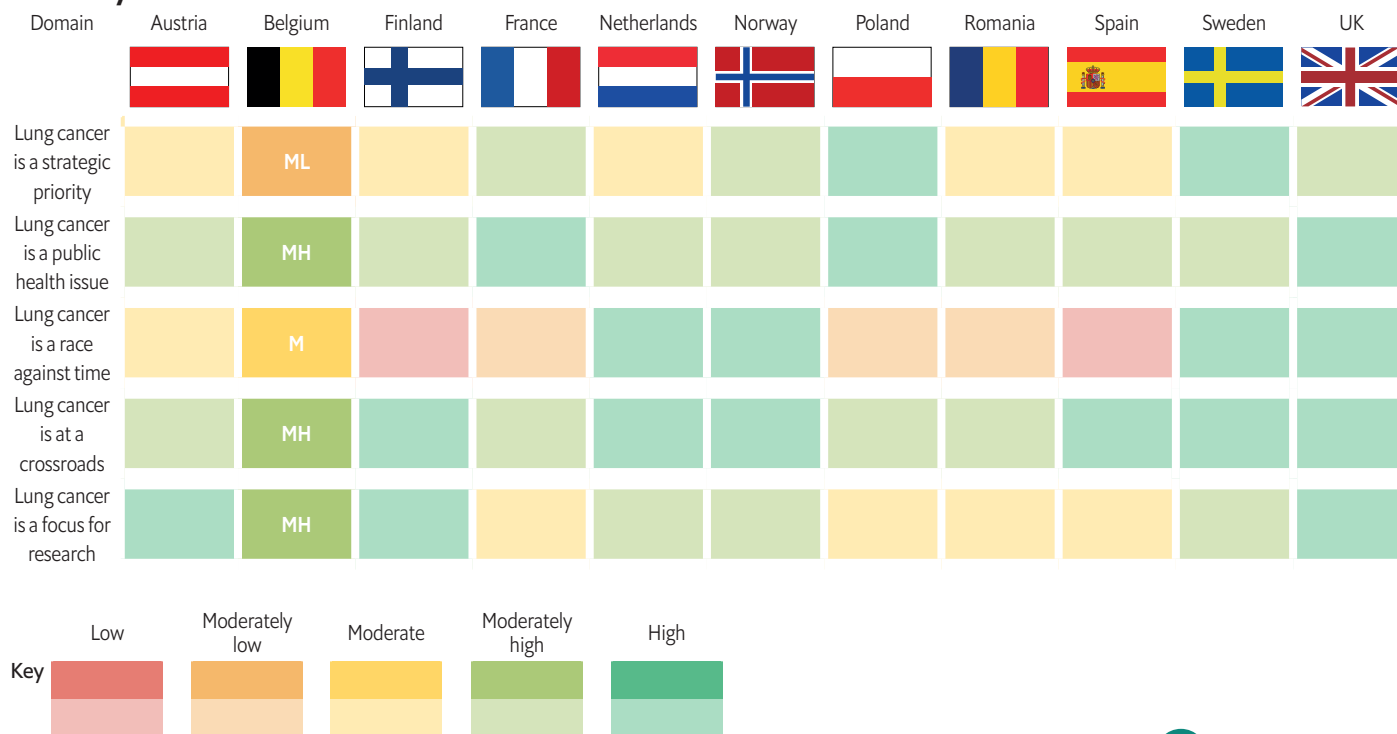


Belgium: Lung Cancer Country Profile

Belgium performs relatively well across all five domains, scoring 'moderately high' in the second, fourth and fifth domains, 'moderate' in the third, and 'moderately low' in the first. To improve scores, Belgium needs to update their National Cancer Control Plan, including an implementation schedule and funding source, and ideally create a lung cancer specific control plan. Guidelines do not cover screening, shared decision-making, or supportive and palliative care. Neither do guidelines mention timeframes for diagnostic testing nor rapid referral to secondary and tertiary care. Strengthening policies on tobacco and involving patient organisations in HTAs can improve the score in the second domain, while the fourth may improve with the 2019 introduction of joint evaluation and reimbursement of biomarker testing and treatment—although not all biomarkers (e.g. PD-L1) are included yet. Inclusion of psychological burden of lung cancer, pathways for psychological support services and supportive and palliative care in guidelines is also needed. We discuss opportunities for improvement at the end of this country profile.

As one of two countries participating in the NELSON trial, Belgium is well-placed to implement its findings and improve early detection rates of lung cancer. The trial demonstrated a reduction in lung cancer mortality with CT screening of high-risk people: individuals were recruited from population-based registries in Belgium and the Netherlands and compared ten-year outcomes between those offered vs those not-offered screening with CT. Workshop participants discussed the importance of screening and early detection. They also noted that awareness of lung cancer should be included in the guidelines used by primary care physicians to assist in early disease detection.

Summary scorecard



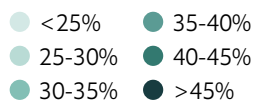
Sponsored by



Belgium

Lung cancer incidence

(Rate per 100,000, 2017)



Belgium

Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Belgium	Europe	Global
Incidence	37	33	27
Prevalence	56	54	41
Mortality	32	27	24
Disability-Adjusted Life Years (DALYs)	711	628	503
Years Lived with Disability (YLDs)	9	8	7
Years of Life Lost (YLLs)	702	619	496

Source: Global Burden of Disease¹

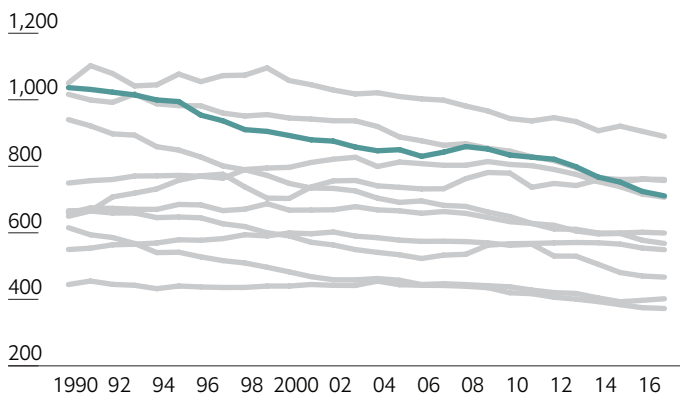
The costs of tobacco

Tobacco costs the economy €9,600 million in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 18,736 deaths in Belgium.²

Burden trend

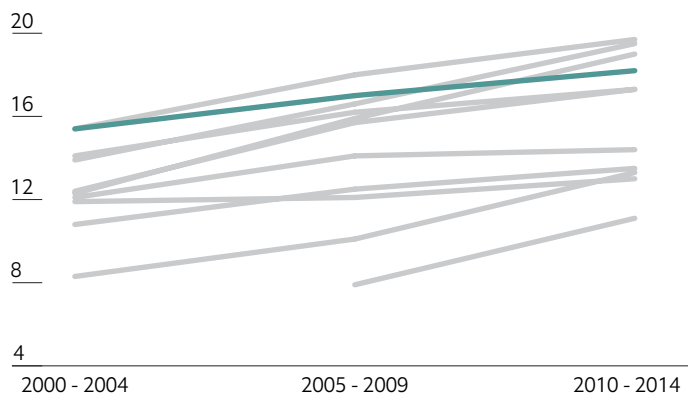
(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

Survival trend

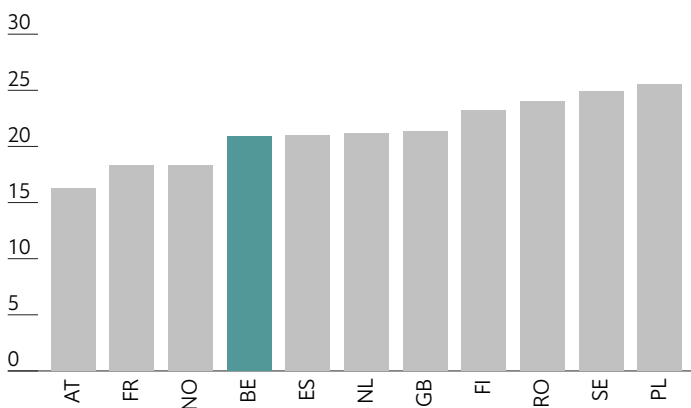
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

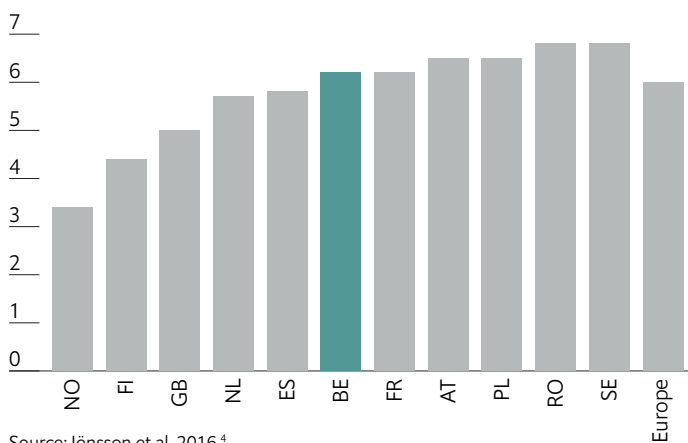
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator	Range	Score	Justification
Lung cancer is a strategic priority			
1 Operational, comprehensive, up to date national cancer control plan	0 – 5	1	<ul style="list-style-type: none"> ● A National Cancer Plan was published by the Ministry of Social Affairs and Public Health in 2008.⁵ ● There is no mention of an implementation plan. While the cancer plan states that it will be accompanied from the outset by an evaluation mechanism, this is not an implementation plan. The Reference Cancer Centre will publish an annual review of the results achieved within the framework of the cancer plan. ● The plan mentions additional funding is available but does not explicitly state the sources of funding. ● A specific lung cancer control plan has not been published by the government or health ministry.
2 Comprehensive clinical guidelines for lung cancer	0 – 6	3	<ul style="list-style-type: none"> ● Lung cancer guidelines were published by KCE (the Belgian Health Care Knowledge Centre) under the supervision of the Minister of Public Health and Social Affairs in 2013.⁶ ● The guidelines mention diagnosis and treatment. ● The guidelines do not mention screening, supportive / palliative care or shared decision making.
Lung cancer is a public health issue			
3 Tobacco control policies and public health measures	0 – 9	6	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁷ ● Belgium is party to World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● According to WHO, no materials were submitted to verify whether a national mass media campaign ran during the survey period (up to 2016). ● National smoke-free legislation exists for public transportation. ● National smoke-free legislation does not exist for indoor offices or restaurants/cafes/pubs/bars but designated smoke free rooms are permitted.
4 E-cigarettes regulation and public health measures	0 – 4	4	<ul style="list-style-type: none"> ● Safety, quality standards and regulation are in place for e-cigarettes. ● The sale of e-cigarettes is prohibited to people under 16 years of age. ● Advertising and sponsorships are prohibited for e-cigarettes with or without nicotine. ● Use of e-cigarettes is forbidden in closed public places and on public transportation (and in all places where tobacco use is banned).
5 National policies and programmes for environmental exposure control	0 – 2	3	<ul style="list-style-type: none"> ● A general EU strategy exists. The Belgian Senate has published a report on establishing a coherent strategy and coordination between local, regional and federal levels on air quality. ● A national radon action plan was published jointly by the Ministry of Health and the Ministry of Sustainable Development, Transport and Housing.
6 Evidence-based approach to lung cancer screening	0 – 1	1	<ul style="list-style-type: none"> ● Belgium is part of a key study in lung cancer screening: the NELSON study. This is a Belgian-Dutch randomised lung cancer screening trial.
7 Patient organisations involvement in policy development	0 – 3	2	<ul style="list-style-type: none"> ● A specific lung cancer patient organisation has not been identified in Belgium. ● The recommendations in the Belgian clinical guidelines were reviewed by representatives of professional associations (stakeholders including patient organisations) using a formal procedure. ● Civil society has no opportunity to comment on HTA recommendations
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	1	<ul style="list-style-type: none"> ● Lung cancer guidelines mention conducting an urgent chest x-ray for red flag symptoms. ● Lung cancer guidelines do not mention a specific timeframe for diagnostic referral for suspected lung cancer patients.
9 Guidelines / pathways for rapid referral to quality care	0 – 2	1	<ul style="list-style-type: none"> ● Lung cancer guidelines do not specifically mention rapid referral for lung cancer patients to secondary or tertiary care. ● Lung cancer guidelines state that all treatment decisions go through a multidisciplinary care team. Urgent referral to a lung cancer multidisciplinary team is made if the patient has problematic symptoms severely affecting quality of life.

Indicator	Range	Score	Justification
Lung cancer is at a crossroads			
10 Medical and surgical specialists	number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2015: 4.7 pulmonologists 11.5 general surgeons 4 oncologists No data on the number of thoracic surgeons.⁸
11 Radiotherapy accessibility	unmet need	unscored	<ul style="list-style-type: none"> ● -28 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -23.3%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	3	<ul style="list-style-type: none"> ● Belgian practice guidelines state that EGFR, ALK and ROS1 testing are recommended for lung cancer samples with at least one ADC component in patients with advanced or recurrent disease. ● Specific markers are identified: EGFR, ALK and ROS1. ● EGFR is reimbursed in Belgium. ● ALK, ROS1 and PD-L1 are not currently reimbursed in Belgium.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not include psychological assessment or mention the psychological burden of lung cancer. ● While mentioned in the national cancer plan, the lung cancer guidelines do not mention a referral pathway to psychological support services.
15 Patient access to supportive / palliative care services	0 – 2	1	<ul style="list-style-type: none"> ● While mentioned in the national cancer plan, the lung cancer guidelines do not mention a referral pathway to supportive / palliative care services. However, the guidelines state that "attention should be given to timely obtaining the patient's wishes (advance care planning) with regard to the planning of care for advanced disease and for palliative care." ● ESMO curriculum includes many competencies on supportive measures, palliative care and end of life care.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	6	<ul style="list-style-type: none"> ● High quality population-based cancer registry (PBCR) (national) (3 points out of a possible 3).⁹ ● Medium quality complete vital registration (3 points out of a possible 4).⁹
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 2.49% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 297.¹⁰ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.6.¹¹

Opportunities for Improvement

Opportunity 1

Recommendation

- Belgium needs an updated National Cancer Control Plan.

Rationale

- *Indicators 1: Belgium's National Cancer Control Plan was published in 2008 and needs to be updated. An updated national cancer control plan should ideally include the following elements—which were only weakly covered at best in the current plan: discussion of prevention, screening and early detection, red flags and symptoms to look for in primary care, diagnosis, an implementation plan and a funding source. A specific lung cancer control plan has not been published by the government or health ministry.*

Opportunity 2

Recommendation

- Referral for diagnostic assessment for patients suspected of having lung cancer should be prioritised within a specified time period as there is currently no mention of rapid referral for diagnostic testing.

Rationale

- *Indicators 8 & 9: Providing a timeframe within which patients suspected of having lung cancer should receive testing is an important milestone for delivery of care as well as having a timeframe for confirmed lung cancer patients to receive secondary or tertiary care. Belgium does not provide such timeframes, nor does it have dedicated fast track referral processes in its lung cancer guidelines. Workshop participants emphasised the importance of timing at every stage of the journey and stressed that a referral pathway needed to specify the workup involved for diagnosis. Participants felt that creating networks between smaller and larger hospital centres could be helpful and that thought could be given to centralising care.*

Opportunity 3

Recommendation

- Ensure that multidisciplinary care teams include a patient's primary care physician in their discussions.

Rationale

- *Indicator 9: Belgium's lung cancer clinical guidelines state that all treatment decisions are reviewed by a multidisciplinary care team. Workshop participants felt that it is important to include the primary care physician in the multidisciplinary care team. While geographical distance may make it challenging to include the primary care physician, it is important that they are seen as part of the team and kept informed of the decisions that are being made. This can ensure that primary care physicians are better informed about the care received and are able to manage their patient's care when the patient returns home.*

Opportunity 4

Recommendation

- The use of molecular testing for lung cancer patients is recommended for patients with advanced or recurring disease and should be reimbursed.

Rationale

- *Indicator 12: Workshop participants emphasised the importance of reimbursement for biomarker testing. While the Belgian lung cancer clinical guidelines recommend the use of histology and molecular testing in patients with advanced or recurring disease, only one of the tests is currently reimbursed.*

Opportunity 5

Recommendation

- Ensure that the psychological burden faced by lung cancer patients is addressed with pathways to access psychological support services. Supportive and palliative care should be included in the lung cancer guidelines.

Rationale

- *Indicators 14 & 15: Belgium neither includes psychological assessment nor mentions the psychological burden of lung cancer in their lung cancer guidelines. Additionally, there is no referral pathway for either psychological support or supportive or palliative care services. (Both are mentioned in the national control plan, but not in guidelines as used by healthcare professionals.) Even though no pathways are provided, the guidelines do acknowledge the issue, saying that: “attention should be given to timely obtaining the patient’s wishes (advance care planning) with regard to the planning of care for advanced disease and for palliative care”. Workshop participants stressed the importance of psychological support for carers. They also noted that supportive and palliative care currently focuses on end of life but should be initiated at the time of diagnosis.*

Opportunity 6

Recommendation

- Cancer registries lack clinical data. In Belgium, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Belgium’s cancer registry and vital registration data collection systems have been evaluated as being of high and medium quality, respectively. Clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. Workshop participants thought that having a real-time digital platform with information on staging would be helpful with a validated questionnaire and trained data managers.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

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Finland: Lung Cancer Country Profile

Finland performs well on the scorecard, scoring 'high' in the treatment and R&D domains, 'moderately high' in the public health domain, but 'low' in the rapid diagnosis domain. Poor performance in this third domain is because the guidelines present neither timeframes nor fast-tracking for diagnostic testing, nor is there a rapid referral pathway to secondary or tertiary care. The National Cancer Control Plan also needs to be updated and include an implementation schedule and funding source. Additionally, the guidelines should discuss shared decision-making. Tobacco and e-cigarette policies could be strengthened and the potential of screening assessed in an evidence based manner. We discuss opportunities for improvement at the end of this country profile.

Including lung cancer in Finland's successful National Respiratory Diseases Programme may offer an opportunity to change attitudes, increase early detection, improve access to treatment, and impact policy. Workshop participants discussed attitudes and stigma towards people with lung cancer. They noted how smokers are often reluctant to bring themselves forward for screening because they feel the shame of a disease they perceive to have brought upon themselves. Participants also spoke about the unconscious bias that some healthcare professionals have towards lung cancer patients. Building awareness about attitudes along with recognising lung cancer as an important respiratory disease to be addressed may help to improve early detection and outcomes in Finland. Due to the dual nature of the Finnish healthcare system where primary and specialised care are sometimes quite distant from patients' treatment perspective, participants felt that increased screening may force clinicians to pay more attention to lung cancer.

Summary scorecard

Domain	Austria	Belgium	Finland	France	Netherlands	Norway	Poland	Romania	Spain	Sweden	UK
Lung cancer is a strategic priority			M								
Lung cancer is a public health issue			MH								
Lung cancer is a race against time			L								
Lung cancer is at a crossroads			H								
Lung cancer is a focus for research			H								

Key	Low	Moderately low	Moderate	Moderately high	High

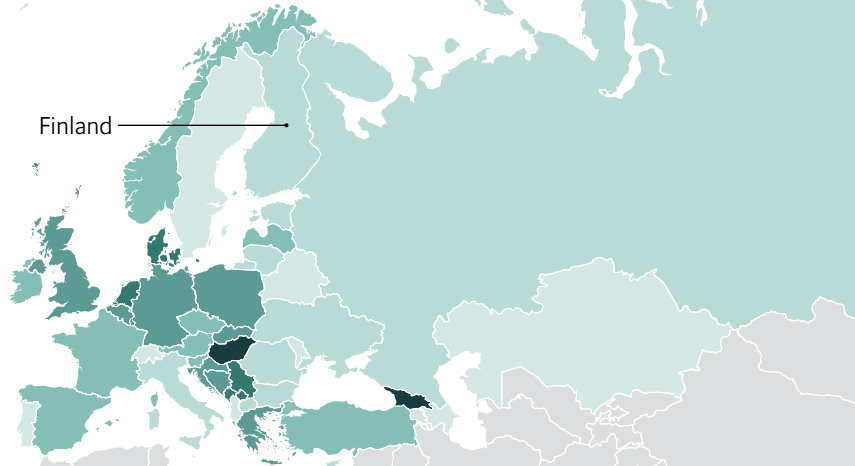
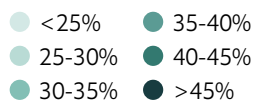
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Finland

Lung cancer incidence

(Rate per 100,000, 2017)



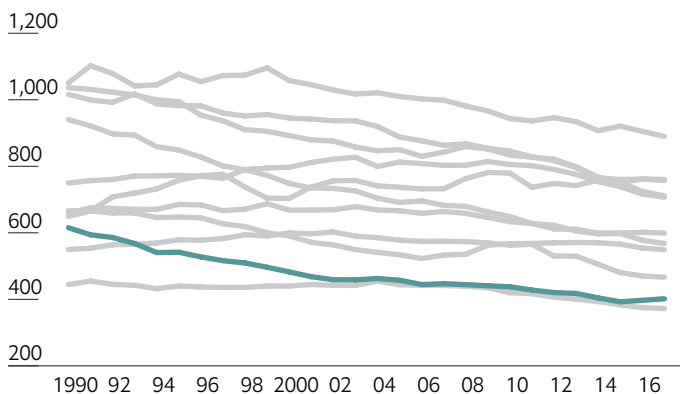
Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Finland	Europe	Global
Incidence	25	33	27
Prevalence	47	54	41
Mortality	20	27	24
Disability-Adjusted Life Years (DALYs)	402	628	503
Years Lived with Disability (YLDs)	7	8	7
Years of Life Lost (YLLs)	395	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

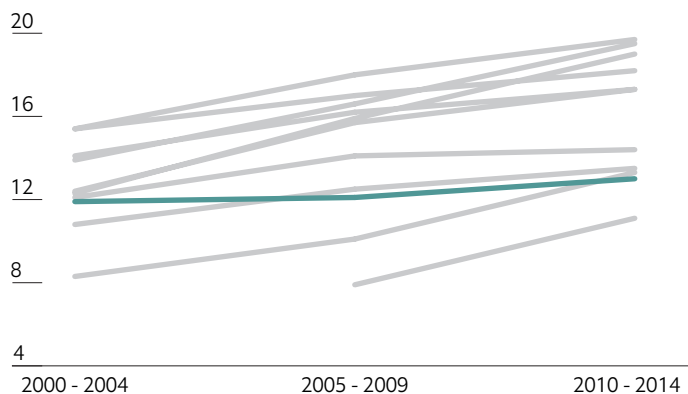
The costs of tobacco

Tobacco costs the economy €2,589 million in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 5,100 deaths in Finland.²

Survival trend

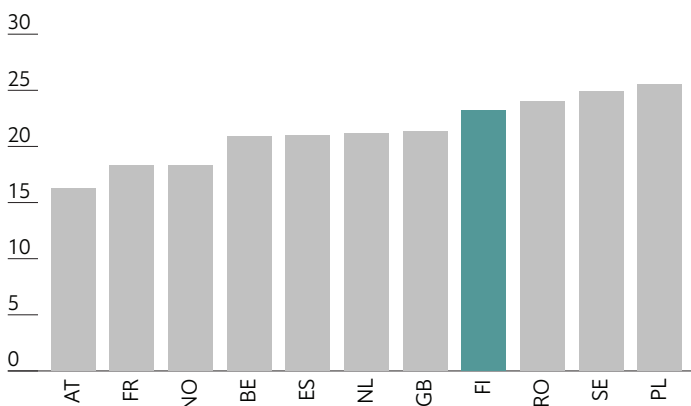
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

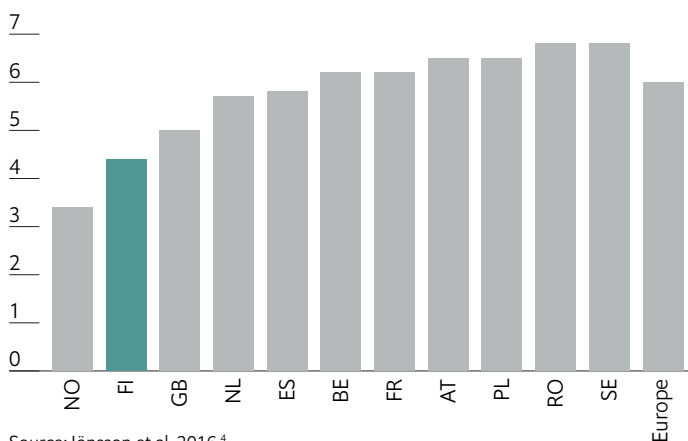
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator	Range	Score	Justification
Lung cancer is a strategic priority			
1 Operational, comprehensive, up to date national cancer control plan	0 – 5	2	<ul style="list-style-type: none"> ● Syövän ehkäisy, varhaisen toteamisen ja kuntoutumisen tuen kehittäminen vuosina 2014–2025 (Cancer Prevention, Early Detection and Developing Support for Rehabilitation, 2014-2025) was published by Terveyden ja Hyvinvoinnin Laitos (Department of Health and Welfare) in 2014.⁵ ● There is no mention of an implementation plan or a funding source. ● A specific lung cancer control plan has not been published by the government or health ministry.
2 Comprehensive clinical guidelines for lung cancer	0 – 6	5	<ul style="list-style-type: none"> ● Lung cancer guidelines were published by the Finnish Medical Society, Finnish Association of Pulmonary Diseases and Finnish Society of Oncology in 2017.⁶ ● Guidelines mention diagnosis and treatment. ● Guidelines include supportive / palliative care as "palliative care aims to provide comprehensive relief of suffering and improve the quality of life in patients who suffer from advanced and incurable disease." ● Guidelines discuss screening, but it is not endorsed as it takes the view that lung cancer screening does not reduce lung cancer mortality. ● Guidelines neither include nor mention shared decision-making.
Lung cancer is a public health issue			
3 Tobacco control policies and public health measures	0 – 9	7	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁷ ● Finland is party to the World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● National smoke-free legislation exists for indoor offices and restaurants/cafes/pubs/bars. ● National smoke-free legislation does not exist for public transportation. ● No data recorded with WHO on whether a national mass media campaign ran during the survey period (up to 2016).
4 E-cigarettes regulation and public health measures	0 – 4	3	<ul style="list-style-type: none"> ● Safety, quality standards and regulation are in place for e-cigarettes. ● The sale of e-cigarettes is prohibited to people under 18 years of age. ● Advertising, promotion and sponsorship (including point-of-sale) is banned. ● Use of e-cigarettes is banned where people under 15 years of age are present and places where smoking is prohibited, including in vehicles.
5 National policies and programmes for environmental exposure control	0 – 2	2	<ul style="list-style-type: none"> ● Finland has an air pollution control plan published by the Ministry of the Environment (2010). An energy and climate strategy published in 2017 includes actions related to air quality published by the Ministry of Economic Affairs and Employment of Finland. ● A radon control programme exists according to WHO. ● Recommendations for radon in dwellings in the Nordic countries (2009) provide risk management recommendations for Finland.
6 Evidence-based approach to lung cancer screening	0 – 1	0	<ul style="list-style-type: none"> ● No data found to show that Finland has conducted a lung cancer screening study or trial.
7 Patient organisations involvement in policy development	0 – 3	1	<ul style="list-style-type: none"> ● A specific lung cancer patient organisation has not been identified in Finland. ● There is a process to involve patient organisations in Health Technology Assessments (HTAs).
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not mention that suspected patients are to be fast tracked. ● Lung cancer guidelines do not mention a specific timeframe for diagnostic referral in suspected lung cancer patients.
9 Guidelines / pathways for rapid referral to quality care	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not mention rapid referral for lung cancer patients to secondary / tertiary care. ● Lung cancer guidelines do not mention referral to a multidisciplinary team to guide treatment plans.

Indicator	Range	Score	Justification
Lung cancer is at a crossroads			
10 Medical and surgical specialists	Number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2014: 3.68 pulmonologists 2.00 thoracic surgeons 8.65 general surgeons 3.2 oncologists.⁸
11 Radiotherapy accessibility	Number of MVM; % unmet need	unscored	<ul style="list-style-type: none"> ● -6 = difference between supply and demand of radiotherapy megavoltage machines (MVM). (minus sign = deficit) ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -11.8%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	5	<ul style="list-style-type: none"> ● Histological and molecular testing are mentioned in the diagnostic guidelines for lung cancer and specific biomarkers are identified. ● EGFR, ALK and PD-L1 tests are reimbursed under national public health system. ● ROS1 is not approved and not reimbursed.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	1	<ul style="list-style-type: none"> ● Lung cancer guidelines include psychological assessment and mention the psychological burden of lung cancer. ● Guidelines do not present a referral pathway to psychological support services.
15 Patient access to supportive / palliative care services	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines view palliative care services as an important component of care and endorse early integration of palliative care services. ● Finland has adopted the ESMO curriculum in their clinical oncology training programme. ESMO curriculum includes many competencies on supportive measures, palliative care and end of life care.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	7	<ul style="list-style-type: none"> ● High quality population-based cancer registry (PBCR) (national) (3 points out of a possible 3).⁹ ● High quality complete vital registration (4 points out of a possible 4).⁹
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 2.75% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 52.¹⁰ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.206.¹¹

Opportunities for Improvement

Opportunity 1

Recommendation

- Participation in lung cancer screening trials and studies may enable Finland to determine whether screening is appropriate for its population.

Rationale

- *Indicator 6: There is no evidence to show that Finland has participated in a lung cancer screening study or clinical trial. It was noted by workshop participants that if targeted screening at primary care was more generally used and healthcare professionals had a chance to ask for screening in case of suspected lung cancer, then lung cancer patients would be taken faster to specialised care. Furthermore, workshop participants stated that increased awareness of lung cancer by the general public could improve early detection.*

Opportunity 2

Recommendation

- Attitudes towards lung cancer and people diagnosed with lung cancer could be improved in Finland. Better understanding of available treatment options may help to change attitudes in the general public. Including lung cancer in Finland's successful National Respiratory Diseases Programme would offer an opportunity to change attitudes, increase early detection, improve access to treatment and impact policy.

Rationale

- *Indicator 14: The stigma of lung cancer was an important issue among workshop participants. Negative attitudes such as blame for having a self-inflicted disease cause many Finns to avoid self-referral, psychosocial support and diagnostic testing. Participants also noted the unconscious bias among some healthcare professionals towards treating lung cancer patients. The Finnish Lung Cancer Association has a successful National Respiratory Diseases Programme which has focused on tuberculosis and asthma in the past. Adding lung cancer to this programme may help to influence policy and lift the stigma of lung cancer in Finland.*

Opportunity 3

Recommendation

- Referral for diagnostic assessment for patients suspected of having lung cancer should be prioritised within a specified time period as there is currently no mention of a rapid referral for diagnostic testing. Additionally, multidisciplinary teams are not mentioned in the lung cancer guidelines.

Rationale

- *Indicators 8 & 9: Providing a timeframe within which patients suspected of having lung cancer should receive testing is an important milestone for delivery of care as well as having a timeframe for confirmed lung cancer patients to receive secondary or tertiary care. Finland does not provide such timeframes, nor does it have dedicated fast-track referral processes in its lung cancer guidelines. Lung cancer guidelines also do not mention the use of multidisciplinary teams to guide treatment plans. These teams can ensure a holistic approach to care.*

Opportunity 4

Recommendation

- The delivery of complex treatment for lung cancer, particularly surgery, may benefit from a centralisation of services.

Rationale

- *Indicators 10 to 13: Workshop participants observed that surgical treatment for lung cancer is currently conducted in many different hospitals. Organising services, such as surgery, within a few centres of excellence may be a better use of limited resources and offer the opportunity to improve outcomes.*

Recommendation

- Cancer registries lack clinical data. In Finland, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Finland's cancer registry and vital registration data collection systems have been evaluated as being of high quality. Clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. Workshop participants noted that disease-specific registries need better information, including data on staging in a national, centralised system. They cautioned that this must not, however, add extra pressure for physicians to input data in 'yet another' registry. It was suggested that, by using technological innovations, it may be possible for a data management system to categorise and sort the data entered, simplifying the data-entry process.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

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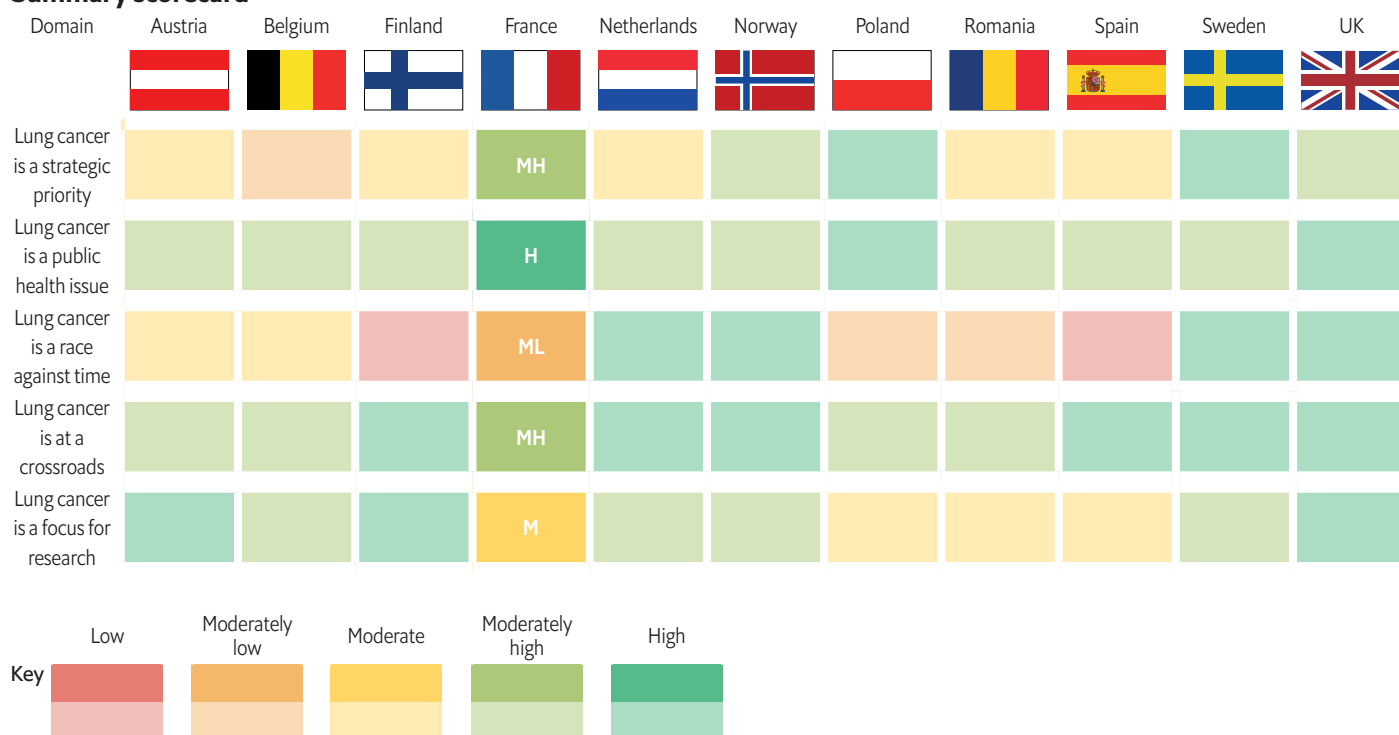


France: Lung Cancer Country Profile

France performs fairly well across all five domains, scoring 'high' in the second domain, 'moderately high' in the first and fourth domains, 'moderate' in the fifth, and 'moderately low' in the third. The third domain's performance is because neither timeframes nor fast-tracking for diagnostic testing is discussed, and there is no rapid referral or pathway to secondary or tertiary care. The fifth domain's performance is because France's cancer registry is rated high quality on a regional basis, not national, and the complete vital registration component is medium quality. The first domain improves with development of a lung cancer specific control plan, identification of a funding source in the National Cancer Control Plan, and a discussion on screening in the clinical guidelines. Addressing reimbursement of histological tests and including psychological support pathways in the guidelines will improve the fourth domain. We discuss opportunities for improvement at the end of this country profile.

There is hope that lung cancer diagnosis and treatment will be aided by the launch in autumn 2019 of the Health Data Hub. The Hub is a unique health database in which a digital patient identity will be developed by matching biologic and behavioural data to provide diagnostic assistance or monitor therapeutic progress. It will encompass a clinical registry, including information on treatment and reimbursement, and combine health data from a range of sources. Workshop participants noted the stigma still surrounding lung cancer in France and stressed the importance of psychological support and palliative care, both of which should be initiated at diagnosis.

Summary scorecard



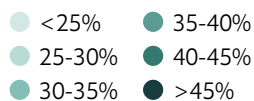
Sponsored by



France

Lung cancer incidence

(Rate per 100,000, 2017)



France

Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	France	Europe	Global
Incidence	34	33	27
Prevalence	49	54	41
Mortality	29	27	24
Disability-Adjusted Life Years (DALYs)	707	628	503
Years Lived with Disability (YLDs)	8	8	7
Years of Life Lost (YLLs)	698	619	496

Source: Global Burden of Disease¹

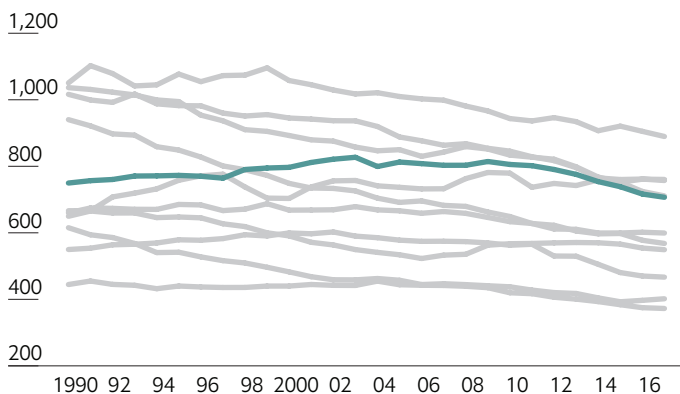
The costs of tobacco

Tobacco costs the French economy €49,922 million in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 73,500 deaths in France.²

Burden trend

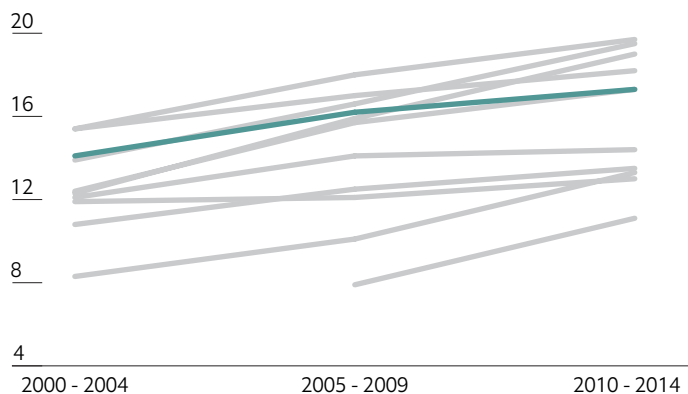
(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

Survival trend

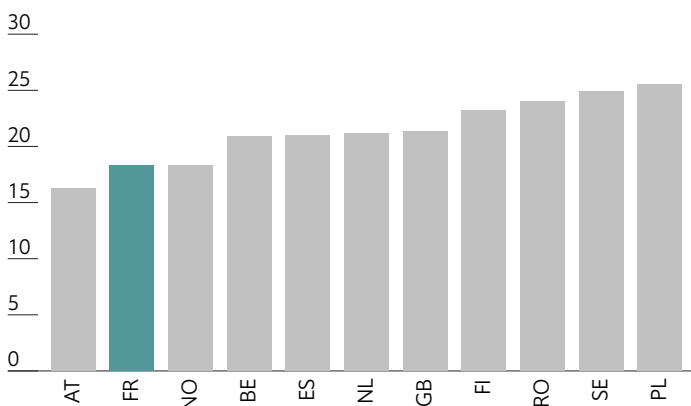
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

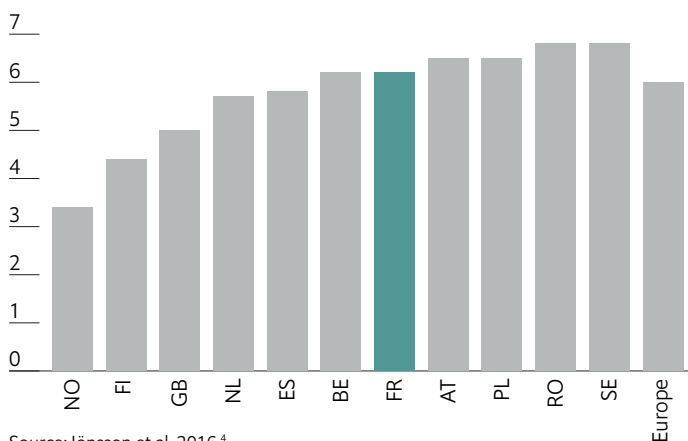
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator	Range	Score	Justification
Lung cancer is a strategic priority			
1 Operational, comprehensive, up to date national cancer control plan	0 – 5	3	<ul style="list-style-type: none"> ● <i>Plan Cancer 2014-2019</i> was published by the Ministry of Social Affairs and Health and the Ministry of Higher Education and Research in 2014.⁶ ● The plan includes an overarching implementation plan. ● A funding source has not been identified within the plan. ● A specific lung cancer control plan has not been published by the government or health ministry.
2 Comprehensive clinical guidelines for lung cancer	0 – 6	5	<ul style="list-style-type: none"> ● The High Authority of Health published the lung cancer guidelines in 2013 and 2014.⁷ ● The guidelines mention diagnosis, treatment, supportive / palliative care and shared decision-making. ● The guidelines do not mention screening. However, the Haute Autorité de Santé (HAS) published in January 2016 an opinion about lung screening and concluded that screening isn't recommended due to safety and efficacy.
Lung cancer is a public health issue			
3 Tobacco control policies and public health measures	0 – 9	8	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁸ ● France is party to World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● At least one national mass media campaign ran during the survey period (up to 2016). ● National smoke-free legislation exists for indoor offices, restaurants/cafes/pubs/bars and public transportation.
4 E-cigarettes regulation and public health measures	0 – 4	4	<ul style="list-style-type: none"> ● Safety, quality standards and regulation are in place for e-cigarettes. ● The sale of e-cigarettes is prohibited to people under 18 years of age. ● Advertising, promotion and sponsorship related to both nicotine and non-nicotine e-cigarettes are prohibited. ● Use of e-cigarettes is prohibited on public transport, enclosed workplaces (as defined by an application decree) and areas with minors.
5 National policies and programmes for environmental exposure control	0 – 2	2	<ul style="list-style-type: none"> ● The <i>Plan National de Surveillance de la Qualité de l'Air Ambient</i> (PNSQA) 2016-2021 defines the organisational, technical and financial structure of the national air quality monitoring system for the period 2016-2021. ● A decree passed in April 2017 lays down provisions for applying the national air quality monitoring system. ● The Institut de radioprotection et de sûreté nucléaire (IRSN) published a report on radon and the WHO cited France's radon control programme.
6 Evidence-based approach to lung cancer screening	0 – 1	1	<ul style="list-style-type: none"> ● A pilot randomised controlled trial of low dose computed tomography screening was launched in 2002.
7 Patient organisations involvement in policy development	0 – 3	3	<ul style="list-style-type: none"> ● Lung cancer patient organisations exist in France. ● Lung cancer guidelines were prepared with participation of a patient representative. ● Patients are involved in Health Technology Assessments (HTAs).
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines neither mention the fast tracking nor any specific timeframe for diagnostic referral for suspected lung cancer patients.
9 Guidelines/ pathways for rapid referral to quality care	0 – 2	1	<ul style="list-style-type: none"> ● Lung cancer guidelines do not mention rapid referral for lung cancer patients to secondary or tertiary care. ● Multidisciplinary teams are mentioned in the lung cancer guidelines to guide treatment plans.

Indicator	Range	Score	Justification
Lung cancer is at a crossroads			
10 Medical and surgical specialists	number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2016: 4.71 pulmonologists 0.72 thoracic surgeons 7.60 general surgeons 1.5 oncologists.⁹
11 Radiotherapy accessibility	unmet need	unscored	<ul style="list-style-type: none"> ● -193 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -28.6%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	2	<ul style="list-style-type: none"> ● In cases of locally advanced or metastatic non-small squamous cell carcinoma, molecular testing is recommended. ● Specific markers are identified: EGFR and ALK. ● PD-L1 is reimbursed from national health insurance. ● EGFR, ALK and ROS1 are reimbursed from hospital budgets once the hospital's annual allocation has been used up.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding of psychological burden of lung cancer and access to support services	0 – 2	1	<ul style="list-style-type: none"> ● Lung cancer guidelines include assessment of a psychologist "according to need." ● Lung cancer guidelines do not mention a referral pathway to psychological support services.
15 Patient access to supportive / palliative care services	0 – 2	1	<ul style="list-style-type: none"> ● Lung cancer guidelines mention a referral pathway to supportive / palliative care services. ● No evidence to demonstrate that oncologists receive training in supportive / palliative care.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	5	<ul style="list-style-type: none"> ● High quality regional population-based cancer registry (PBCR) (regional) (2 points out of a possible 3).¹⁰ ● Medium quality complete vital registration (3 points out of a possible 4).¹⁰
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 2.25% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 609.¹¹ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.235.¹²

Opportunities for Improvement

Opportunity 1

Recommendation

- Participation in lung cancer screening trials and studies may enable France to determine whether screening is appropriate for its population.

Rationale

- *Indicator 6: While a pilot trial of low-dose computed tomography screening was launched in France in 2002, there is no information on any recent evidence-based approaches to lung cancer screening. Workshop participants suggested that an experimental screening programme may start in some target areas in 2020. Decisions on this and whether it will be regional or national will be based upon the publication of the NELSON study. In 2016 HAS stated that they do not consider that there is sufficient scientific evidence to demonstrate that lung cancer screening can impact disease management.*

Opportunity 2

Recommendation

- Referral for diagnostic assessment for patients suspected of having lung cancer should be prioritised within a specified time period as there is currently no mention of a rapid referral for diagnostic testing.

Rationale

- *Indicators 8 & 9: Providing a timeframe within which patients suspected of having lung cancer should receive testing is an important milestone for delivery of care as well as having a timeframe for confirmed lung cancer patients to receive secondary or tertiary care. France does not provide such timeframes, nor does it have dedicated fast track referral processes in its lung cancer guidelines. Workshop participants noted, however, that some Parisian centres use a fast track system.*

Opportunity 3

Recommendation

- Decreasing the time between EMA approval and reimbursement may improve access for patients to innovations in care.

Rationale

- *Indicator 13: Workshop participants cited the challenging gap between EMA approval and reimbursement in France. Access in clinical trials and through compassionate use can help to alleviate some of the pressures in the short term. Longer term it is important to try and ensure that medications are available—in a financially sustainable manner—as soon as possible after they have been approved. Because hospitals pay for treatment, at the moment there is a two-tiered system between patients treated in hospitals whose budgets allow for the financing of treatments (otherwise not yet reimbursed) and those whose budgets do not allow it.*

Opportunity 4

Recommendation

- The use of molecular testing for lung cancer should be accessible for patients with advanced or recurring lung cancer.

Rationale

- *Indicator 12: Workshop participants emphasised the importance of reimbursement for biomarker testing. While the French lung cancer clinical guidelines recommend the use of histology and molecular testing in patients with locally advanced or metastatic non-small squamous cell carcinoma, the system of reimbursement is complex and not comprehensive. Participants noted that current funding is not sufficient due to the number of tests needed. Currently, the prescriber pays for the test from an annual budget, then once that budget is depleted the hospital pays—if it can afford to do so—from its own funds. France should take steps to safeguard equitable access to testing.*

Opportunity 5

Recommendation

- Ensure that the psychological burden faced by lung cancer patients is addressed with pathways to access psychological support services.

Rationale

- *Indicator 14: While France includes a psychological assessment “according to need,” they do not provide a pathway for obtaining psychological support services in their lung cancer guidelines. Workshop participants noted the importance of addressing the psychological, supportive and palliative care needs of lung cancer patients from the time of diagnosis. They note that a visit to a psychologist following diagnosis is specified in the guidelines. However there is no funding for further psychological treatment; patients pay for it out of pocket.*

Opportunity 6

Recommendation

- Ensure that oncologists receive training in supportive and palliative care.

Rationale

- *Indicator 15: There is no evidence to demonstrate that training in supportive and palliative care is integrated into the training of oncologists in France. Training ensures that clinicians understand the importance of supportive and palliative care (not just end of life care) that can meet the needs of their patients.*

Opportunity 7

Recommendation

- Cancer registries lack clinical data. In France, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: France’s cancer registry has been evaluated to be at a high quality at a regional basis (though not at a national base), and its vital registration data collection systems have been evaluated as being of medium quality. Clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. France’s new Health Data Hub will be an important step forward in achieving improvements. The Hub will improve the ability to analyse results as it will encompass a clinical registry as well as information on treatment and reimbursement.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

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References

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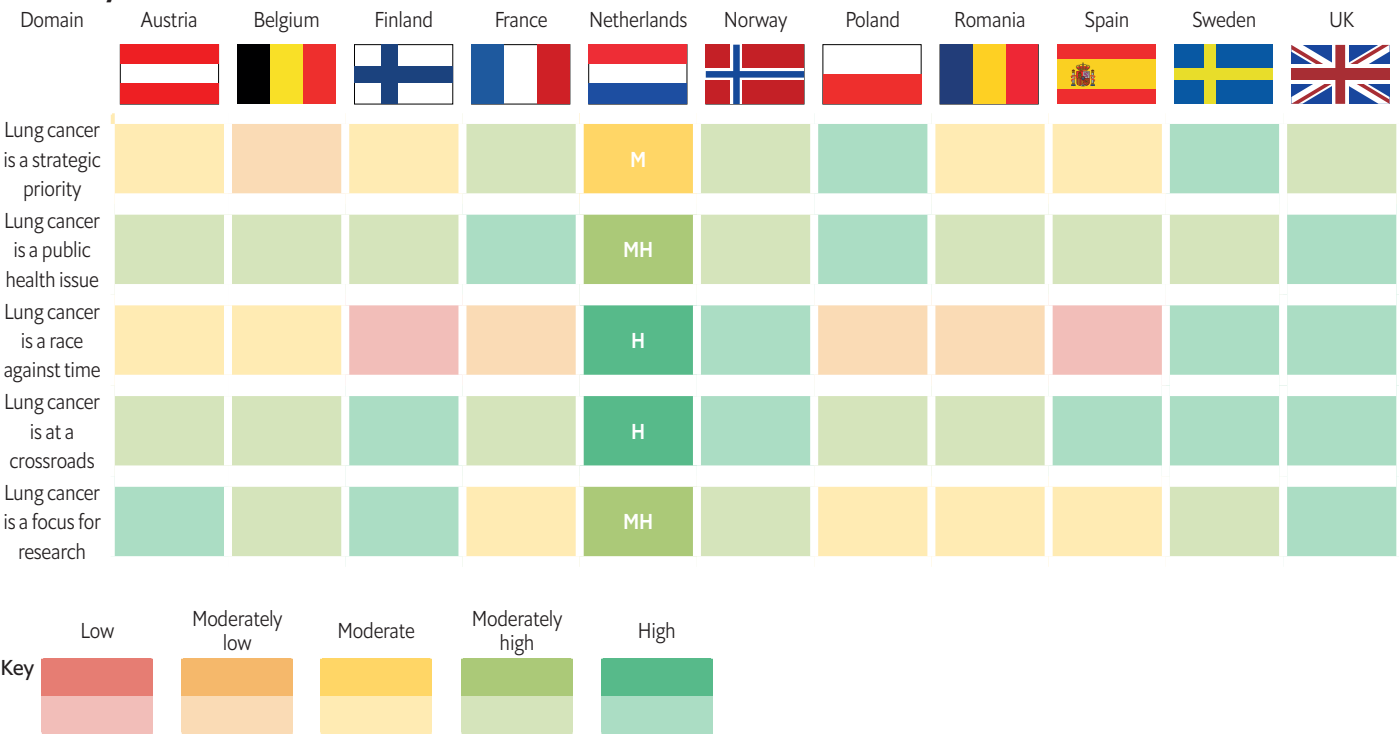


Netherlands: Lung Cancer Country Profile

The Netherlands performs well across all five of the domains, scoring ‘high’ in the third and fourth domains on diagnosis and treatment and ‘moderately high’ in the second and fifth domains on public health and R&D. In the first domain, on strategy, the Netherlands scored only moderately well because the National Lung Cancer Control Plan needs to be updated and include an implementation schedule and funding source; also, there is no specific lung cancer control plan. Policies on tobacco and e-cigarette use could also be strengthened, and complete vital registration data collection of the Netherlands is only medium quality. Scores in the treatment domain could be improved by discussing the psychological burden of lung cancer. We discuss opportunities for improvement at the end of this country profile.

As one of the two countries participating in the NELSON trial, the Netherlands is well-placed to implement its findings and improve early detection rates of lung cancer. The trial demonstrated a reduction in lung cancer mortality with CT screening of high-risk people: individuals were recruited from population-based registries in the Netherlands and Belgium and compared ten-year outcomes between those offered vs those not-offered screening with CT. Understanding what steps can be taken to address the primary causes of lung cancer through efforts to impact smoking prevention and cessation, tobacco pricing and taxation, as well as considering the cost of insurance premiums for smokers, were all issues important to workshop participants.

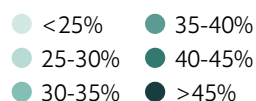
Summary scorecard



Netherlands

Lung cancer incidence

(Rate per 100,000, 2017)



Netherlands

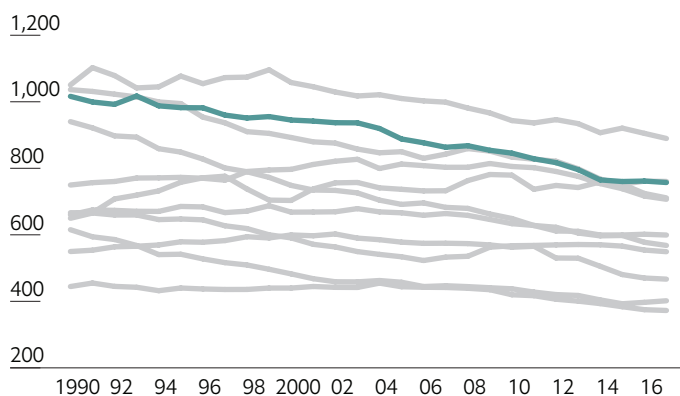
Lung cancer in numbers

Lung cancer statistics	Netherlands	Europe	Global
Rate per 100,000, 2017			
Incidence	44	33	27
Prevalence	79	54	41
Mortality	36	27	24
Disability-Adjusted Life Years (DALYs)	757	628	503
Years Lived with Disability (YLDs)	11	8	7
Years of Life Lost (YLLs)	746	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

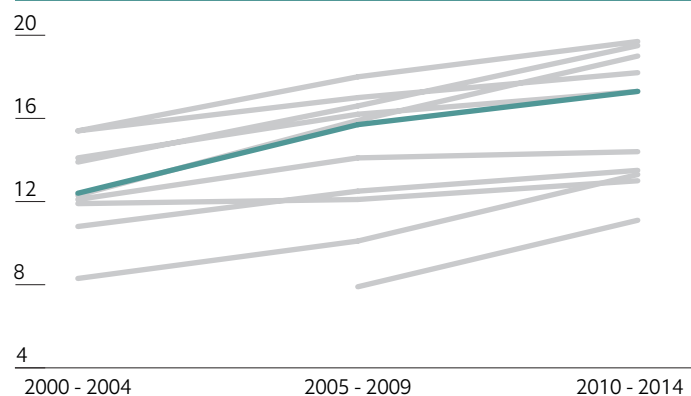
The costs of Tobacco

Tobacco costs the economy €16,933 in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 29,900 deaths in the Netherlands.²

Survival trend

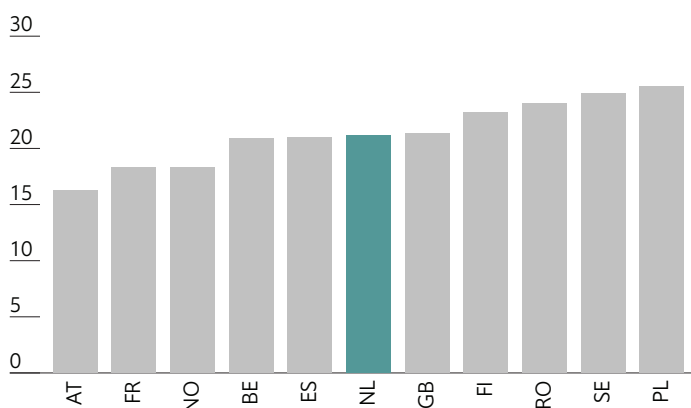
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

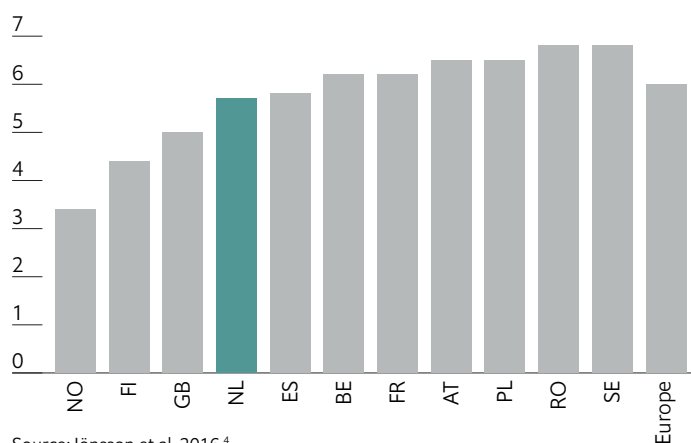
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator	Range	Score	Justification
Lung cancer is a strategic priority			
1 Operational, comprehensive, up to date national cancer control plan	0 – 5	1	<ul style="list-style-type: none"> ● The National Cancer Control Programme (NPK) published the 'NPK Vision and Summary 2005 - 2010' in 2005. A progress report was published in 2010.⁵ ● There is no mention of an implementation plan; the plan states that implementation of the action plans will be assessed annually. ● The proposed plan is said to be "budgetary neutral" and that it will be "financed by reallocation of existing resources and from efficiency gains." We are unsure how fiscally sound this could be. Additionally, this does not take into account the time lag between attaining efficiencies and the funds being made available to invest in cancer. ● A specific lung cancer control plan has not been published by the government or health ministry.
2 Comprehensive clinical guidelines for lung cancer	0 – 6	6	<ul style="list-style-type: none"> ● National Working Group on Lung Tumours published Niet kleincellig longcarcinoom Landelijke richtlijn, Versie: 2.2, the national guidelines in 2015.⁶ ● Guidelines mention screening with low-dose CT. Specifically, the guidelines state "lung carcinoma screening is advised in high-risk groups, by centres that have one low-dose CT and specific software. In addition, there must be knowledge and skills for screening present. Stopping smoking is an integral part of screening." Yet, the guidelines go on to state there are "uncertainties about the value of these recommendations for clinical practice." ● Guidelines cover diagnosis, treatment, supportive / palliative care and shared decision making.
Lung cancer is a public health issue			
3 Tobacco control policies and public health measures	0 – 9	6	<ul style="list-style-type: none"> ● Government objectives on tobacco control and a national agency for tobacco control exists.⁷ ● Netherlands is party to World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● At least one national mass media campaign ran during the survey period (up to 2016). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● According to WHO, national smoke-free legislation does not exist for indoor offices, restaurants/cafes/pubs/bars or public transportation because smoking rooms are permitted.
4 E-cigarettes regulation and public health measures	0 – 4	2	<ul style="list-style-type: none"> ● E-cigarettes are regulated by law: safety, quality standards and regulation are in place. ● The sale of nicotine-containing and non-nicotine e-cigarettes and e-liquids is prohibited to people under 18 years of age. ● No complete ban exists for e-cigarette advertising: while e-cigarette and e-liquid advertisement is prohibited, there are exceptions (e.g. advertising is permitted in tobacco or e-cigarette specialist shops). It is prohibited to give away free samples of e-cigarettes. ● E-cigarette use is not banned in one or more public areas when the e-cigarettes do not contain tobacco.
5 National policies and programmes for environmental exposure control	0 – 2	2	<ul style="list-style-type: none"> ● The Dutch National Air Quality Cooperation Programme (NSL) established to ensure the Netherlands met EU standards. ● WHO states that the Netherlands has a radon control programme..
6 Evidence-based approach to lung cancer screening	0 – 1	1	Netherlands is a vital part of a key study in lung cancer screening, the NELSON study, a Dutch Belgian randomised lung cancer screening trial.
7 Patient organisations involvement in policy development	0 – 3	3	<ul style="list-style-type: none"> ● A specific lung cancer patient organisation has been identified in the Netherlands. ● Patient representative included in clinical guideline development. ● Civil society has the opportunity to comment on HTA recommendations

Indicator	Range	Score	Justification
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines recommend that GPs ensure 80% of suspected patients should be referred to diagnostic referral within 2 working days, at most 3 working days. 80% of patients must complete the diagnostic process (CT scan, bronchoscopy, PET) within 3 weeks.
9 Guidelines/ pathways for rapid referral to quality care	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines recommend that pulmonologists ensure 80% of patients are referred within 5 working days if there is evidence of a lung tumour or abnormalities in the chest x-ray. Curative therapy should begin for 80% of patients within 2 weeks of diagnosis and palliative therapy should begin for 80% of patients within 1 week of diagnosis. ● Multidisciplinary team referral mentioned to guide treatment plans and stated as being indispensable in all phases of diagnosis and treatment.
Lung cancer is at a crossroads			
10 Medical and surgical specialists	number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2015: 5.12 pulmonologists 0.93 thoracic surgeons 9.73 general surgeons No data on number of oncologists.⁸
11 Radiotherapy accessibility	unmet need	unscored	<ul style="list-style-type: none"> ● -43 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -25.3%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	6	<ul style="list-style-type: none"> ● Lung cancer guidelines mention histological and molecular testing. ● Specific markers are identified: EGFR and ALK. ● EGFR, ALK, ROS1 and PD-L1 approved and reimbursed.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	1	<ul style="list-style-type: none"> ● Lung cancer guidelines include psychological assessment and mention the psychological burden of lung cancer. ● Guidelines do not include a pathway to psychological support services.
15 Patient access to supportive / palliative care services	0 – 2	1	<ul style="list-style-type: none"> ● IKNL guidelines present a palliative care framework published in October 2017. ● Training in supportive / palliative care is not integrated into the training of oncologists in the Netherlands.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	6	<ul style="list-style-type: none"> ● High quality population-based cancer registry (PBCR) (national) (3 points out of a possible 3).⁹ ● Medium quality complete vital registration (3 points out of a possible 4).⁹
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 2.03 of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 408.¹⁰ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.49.¹¹

Opportunities for Improvement

Opportunity 1

Recommendation

- The Netherlands needs an updated National Cancer Control Plan.

Rationale

- *Indicator 1: The Netherlands' National Cancer Control Programme (NPK), a multi-stakeholder partnership, published the "NPK Vision and Summary 2005-2010" in 2005. A progress report was published in 2010. The plan needs to be updated. An updated national cancer control plan should ideally include the following elements: discussion of prevention, screening and early detection, red flags and symptoms to look for in primary care, diagnosis, an implementation plan and a funding source. Workshop participants agreed that an updated plan should look to improve the processes used to assess innovations in care. Participants also noted that a focus on lung cancer is missing in the guidelines used in general practice, plus that there needs to be a focus on early diagnoses, enhanced transparency of treatment options, and improved quality of care.*

Opportunity 2

Recommendation

- Ensure that the psychological burden faced by lung cancer patients is addressed with pathways to access psychological support services.

Rationale

- *Indicator 14: While the Netherlands' guidelines include a discussion of the psychological burden of lung cancer and the importance of psychological assessment, they do not provide a pathway for obtaining relevant support services in their lung cancer guidelines. Providing a pathway in the guidelines provides clear and practical steps to ensure that patients can receive the support that they need.*

Opportunity 3

Recommendation

- Ensure that oncologists receive training in supportive and palliative care.

Rationale

- *Indicator 15: Training in supportive and palliative care is not integrated into the training of oncologists in the Netherlands. Training ensures that clinicians understand the importance of supportive and palliative care—particularly the importance of discussing this at time of diagnosis—and can better meet the needs of their patients.*

Opportunity 4

Recommendation

- Cancer registries lack clinical data. In the Netherlands, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: The Netherlands' cancer registry and vital registration data collection systems have been evaluated as being of high and medium quality, respectively. Clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. Workshop participants noted that registries need better information, including data on staging. Finally it was suggested that data registration could benefit from more central planning and co-ordination, and that access to real world evidence would benefit a range of stakeholders.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

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1. Institute for Health Metrics and Evaluation (IHME). GBD Results Tool. [Internet]. Seattle, WA: University of Washington; [cited 3 June 2019]. Available from: <http://ghdx.healthdata.org/gbd-results-tool>.
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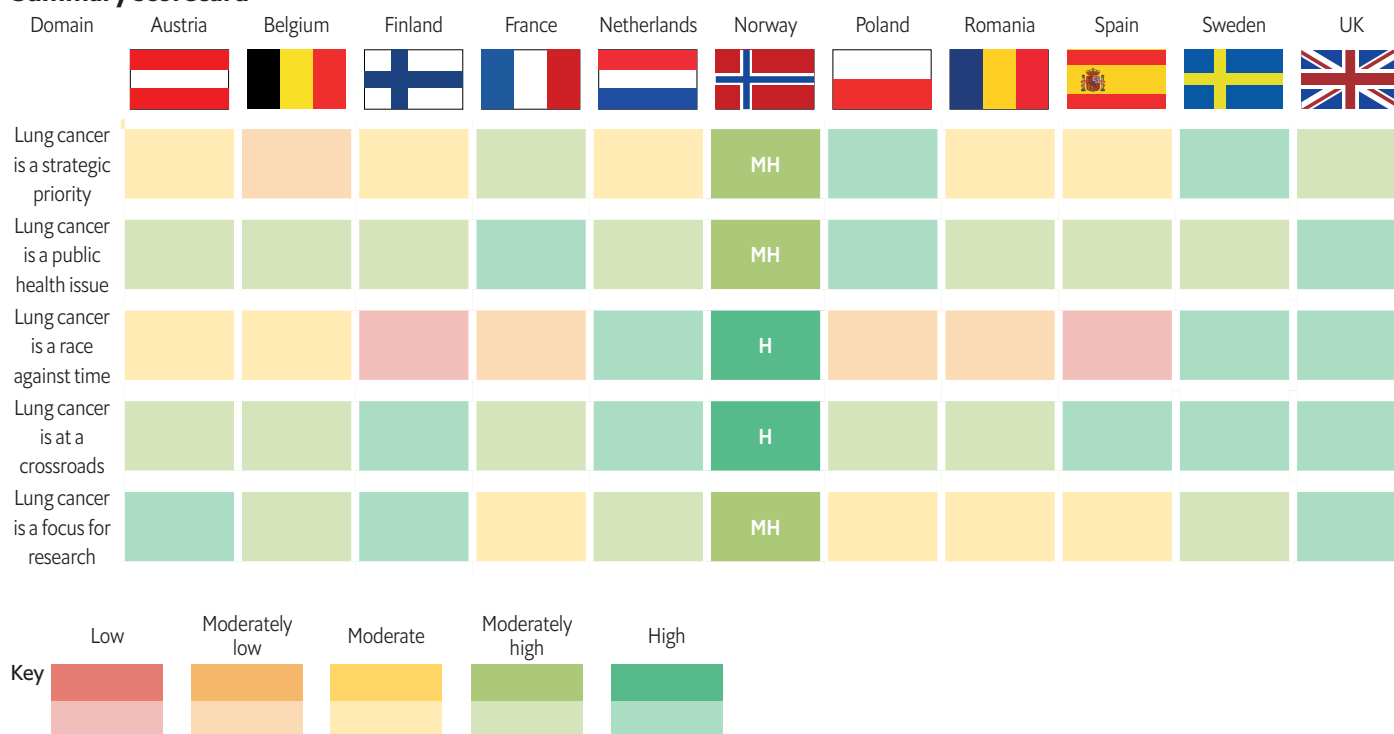


Norway: Lung Cancer Country Profile

Norway performs well across all five of the domains, scoring 'high' in the third and fourth domains (on diagnosis and treatment, respectively) and 'moderately high' in the remaining three domains. In the first domain, which looks at lung cancer as a strategic priority, scores could be improved with the development of a lung cancer specific control plan and ensuring that the National Cancer Control Plan includes an implementation schedule and a funding source. The second domain, focused on the public health aspects of lung cancer, could be improved by an evidence based approach to screening and the involvement of patient organisations in HTA assessments. The fifth domain scores slightly lower because the complete vital registration is just of medium quality. However, in 2019, the INSPIRE project was launched to improve the quality of lung cancer data gathered. We discuss opportunities for improvement at the end of this country profile.

It is important that Norway, with its disparate population, addresses the challenge of centralising care, particularly diagnosis and surgical treatment, while using technology to ensure that high quality care can be delivered in remote regions. While improved access to innovative treatment is being explored in Norway, workshop participants noted that delays in reimbursement resulted in delayed access for patients. Workshop participants also underscored the importance of addressing lung cancer by working to strengthen prevention efforts; those that smoke need help to stop, while those that don't smoke need to be encouraged not to start. Prevention is better than cure.

Summary scorecard



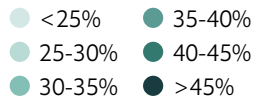
Sponsored by



Norway

Lung cancer incidence

(Rate per 100,000, 2017)



Norway

Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Norway	Europe	Global
Incidence	30	33	27
Prevalence	66	54	41
Mortality	22	27	24
Disability-Adjusted Life Years (DALYs)	467	628	503
Years Lived with Disability (YLDs)	8	8	7
Years of Life Lost (YLLs)	458	619	496

Source: Global Burden of Disease¹

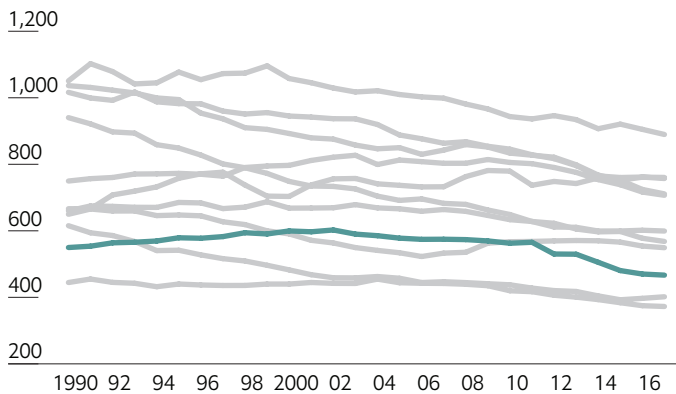
The costs of Tobacco

Tobacco costs the Norwegian economy 44,319 million kroner in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 6,200 deaths in Norway.²

Burden trend

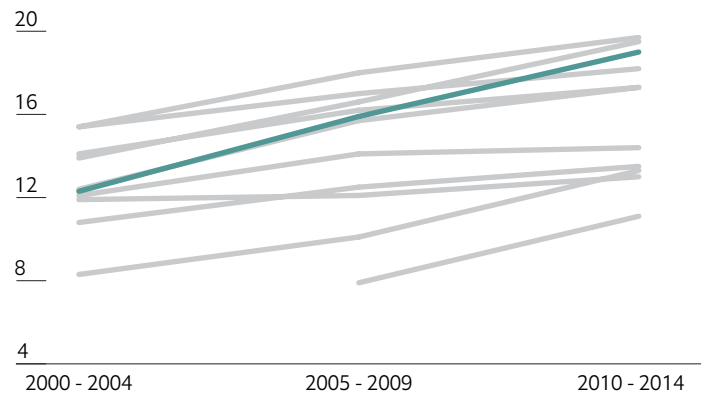
(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

Survival trend

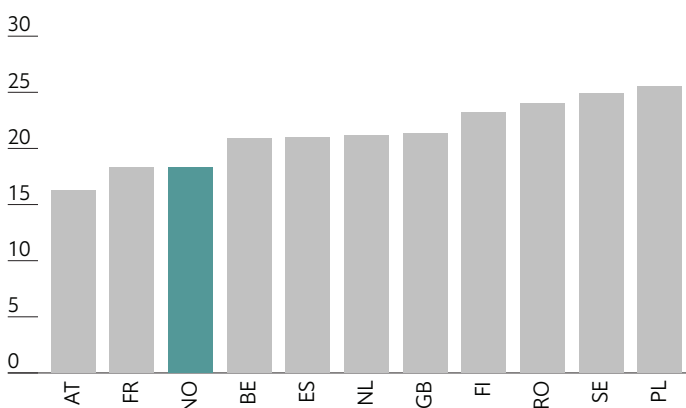
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

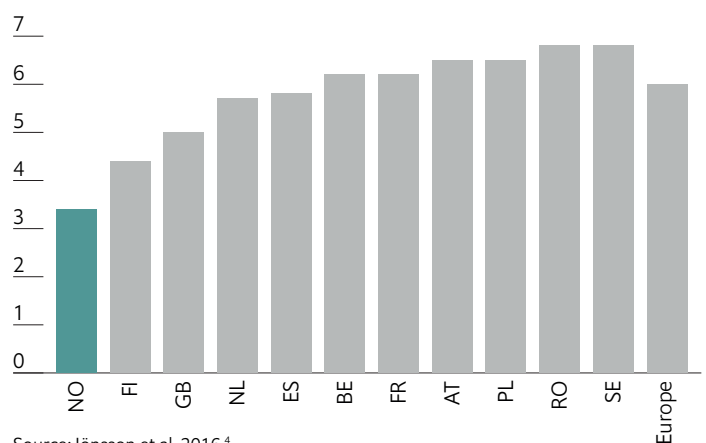
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator	Range	Score	Justification
Lung cancer is a strategic priority			
1 Operational, comprehensive, up-to-date national cancer control plan	0 – 5	3	<ul style="list-style-type: none"> ● An operational National Cancer Strategy 2018-2022 was published by the Norwegian Ministry of Health and Care Services in 2018.⁴ ● The National Cancer Strategy mentions an implementation plan. ● The National Cancer Strategy does not mention a funding source. ● A specific lung cancer control plan has not been published by the government or health ministry.
2 Comprehensive clinical guidelines for lung cancer	0 – 6	6	<ul style="list-style-type: none"> ● The Directorate of Health published lung cancer guidelines in 2016 which were updated in 2019.⁵ ● The guidelines mention screening and cover diagnosis, treatment, supportive / palliative care and shared decision making.
Lung cancer is a public health issue			
3 Tobacco control policies and public health measures	0 – 9	9	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁶ ● Norway is party to the World Health Organization's Framework Convention on Tobacco Control (FCTC). ● At least one national mass media campaign ran during the survey period (up to 2016). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● National smoke free legislation exists for indoor offices, restaurants/cafes/pubs/bars and public transportation.
4 E-cigarettes regulation and public health measures	0 – 4	4	<ul style="list-style-type: none"> ● E-cigarettes can be classified either as medicinal products or as tobacco surrogates. Regulation bans the import and sale of nicotine-containing e-cigarettes, but if products are classified as medicines, they may be imported for private use. ● The sale of e-cigarettes is prohibited to people under 18 years of age. ● Advertising and point of sale display advertising are banned. ● E-cigarette use in all public venues, transport vehicles, restaurants / bars and at schools is prohibited under the smoking ban.
5 National policies and programmes for environmental exposure control	0 – 2	1	<ul style="list-style-type: none"> ● There is no air quality strategy in Norway. ● The Norwegian government published its national strategy for reducing radon exposure in 2009.
6 Evidence-based approach to lung cancer screening	0 – 1	0	<ul style="list-style-type: none"> ● No data found to show that Norway has conducted a lung cancer screening study or trial.
7 Patient organisations involvement in policy development	0 – 3	1	<ul style="list-style-type: none"> ● An independent lung cancer patient organisation exists in Norway; however, it was not involved in the lung cancer guideline development. ● There is no process for civil society involvement in Health Technology Assessments (HTAs).
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	2	<ul style="list-style-type: none"> ● Guidelines mention suspected lung cancer patients are to be fast tracked. ● Guidelines mention specific timeframe for diagnostic referral in suspected lung cancer patients: a chest x-ray is to be done within 1 day.
9 Guidelines/ pathways for rapid referral to quality care	0 – 2	2	<ul style="list-style-type: none"> ● There is a pathway for rapid referral for lung cancer patients to secondary / tertiary care. ● Guidelines recommend that patients are treated by a multidisciplinary team.

Indicator	Range	Score	Justification
Lung cancer is at a crossroads			
10 Medical and surgical specialists	Number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2015: 3.70 pulmonologists 1.06 thoracic surgeons 8.62 general surgeons 4.2 oncologists.⁷
11 Radiotherapy accessibility	Number of MVM; % unmet need	unscored	<ul style="list-style-type: none"> ● -8 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit.) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -16.3% ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	6	<ul style="list-style-type: none"> ● Norwegian lung cancer guidelines recommend molecular testing. ● Specific markers are identified: EGFR, ALK, ROS1. ● Tests are approved and reimbursed: EGFR, ALK, ROS1 and PD-L1.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	2	<ul style="list-style-type: none"> ● The Norwegian lung cancer pathway includes psychological assessment and mentions the psychological burden of lung cancer. ● There is a referral pathway to psychological support services.
15 Patient access to supportive / palliative care services	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines mention a referral pathway to supportive / palliative care services. ● Physicians specializing in oncology have a mandatory rotation in a palliative care unit.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	6	<ul style="list-style-type: none"> ● High quality population-based cancer registry (national) (3 points out of a possible 3).⁸ ● Medium quality complete vital registration (3 points out of a possible 4).⁸
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 2.03% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 77.⁹ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.19.¹⁰

Opportunities for Improvement

Opportunity 1

Recommendation

- Participation in lung cancer screening trials and studies may enable policymakers to determine whether screening is appropriate for Norway. Norway has not participated in an evidence based approach on lung cancer screening.

Rationale

- *Indicator 6: We did not find any indication that Norway has conducted a lung cancer screening study or trial. Workshop participants noted that results from the NELSON trial will be reviewed to assess opportunities for implementation in Norway.*

Opportunity 2

Recommendation

- Decreasing the time between EMA approval and reimbursement of new treatments is important to provide Norwegians with the latest innovations in care. Earlier access to new treatments through clinical trials and compassionate use programmes can help in the short term.

Rationale

- *Indicator 13: Workshop participants cited the challenging gap between EMA approval and reimbursement in Norway. Access to clinical studies and compassionate use can help to alleviate some of the pressure in the short term. Longer term it is important to ensure that medications are available—in a financially sustainable manner—as soon as reasonably possible after they have been approved. Failing to do so can create a two-tiered system whereby only those who can afford to pay for the medication obtain access.*

Opportunity 3

Recommendation

- A national plan for quality assurance for diagnosis and a centralised programme for diagnostic services could improve care in Norway.

Rationale

- *Indicator 8: Workshop participants recommended that Norway move towards greater centralisation of diagnostic and surgical services coupled with a decentralised programme to allow patients to receive treatment near their homes. For health systems servicing a decentralised population, such a hub and spoke model offers many potential benefits.*

Opportunity 4

Recommendation

- Involvement of patient organisations in national assessments of disease and policy development can help to build consensus.

Rationale

- *Indicator 7: A specific lung cancer patient organisation exists in Norway, but there is no evidence that patients were represented in clinical guideline development. Involving patients in the development of clinical guidelines can 1) help to identify issues that may be overlooked by health professionals, 2) influence the development of recommendations from a patient and carer perspective, and 3) emphasise the importance of including shared decision making. A defined structure for obtaining patient involvement is key, and workshop participants suggested that the Norwegian Medical Agency is developing a new system to increase the role of patient organisations in public procurement.*

Recommendation

- Cancer registries lack clinical data. In Norway, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Norway's cancer registry has been evaluated to be at a high quality at a national basis, and its vital registration data collection systems have been evaluated as being of medium quality. Clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

References

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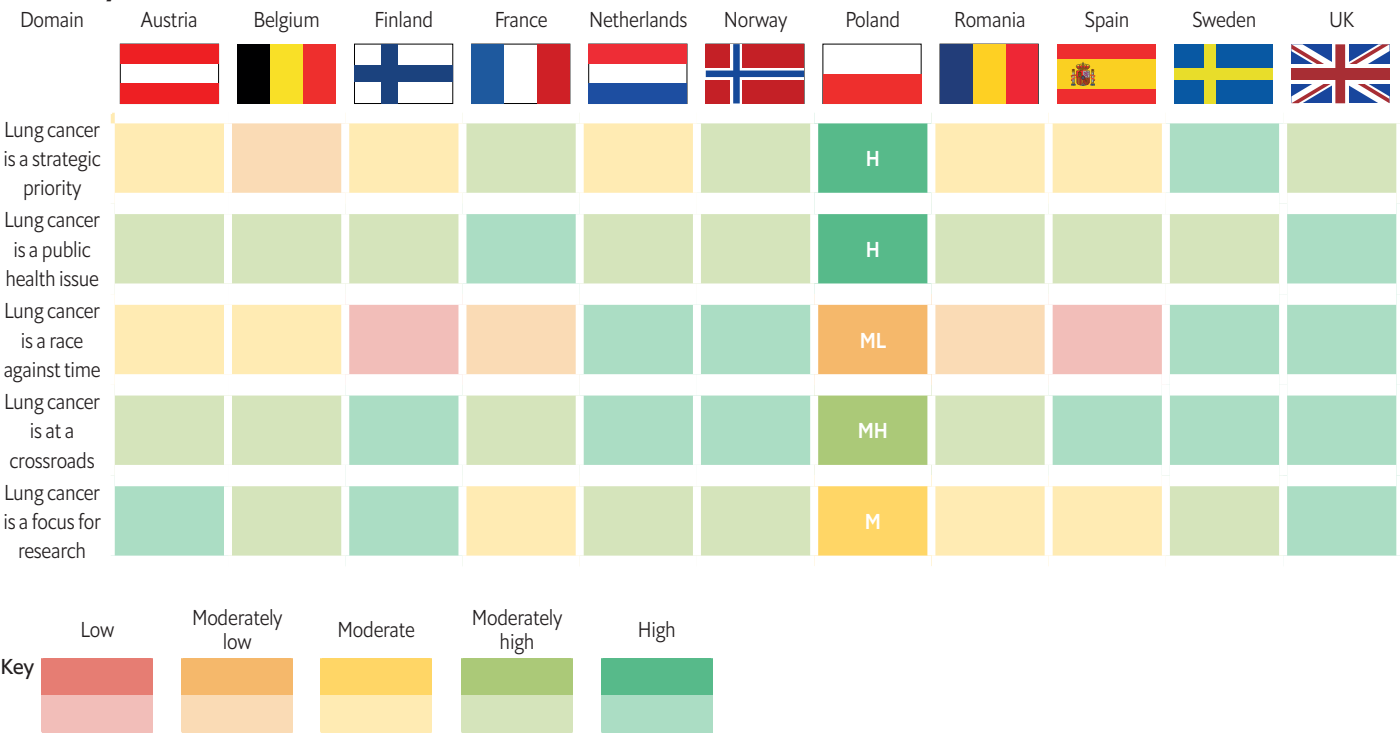


Poland: Lung Cancer Country Profile

Poland performs moderately well across all five of the domains, scoring ‘high’ in the first domain on strategy, and the second domain on public health. Poland performs moderately low in the third domain, on rapid diagnosis, because the guidelines present neither timeframes nor fast tracking for diagnostic testing, nor is there a rapid referral pathway to secondary or tertiary care. Poland performs only moderately in the fifth domain because while the cancer registry is highly rated, it is only regional rather than national, and the complete vital registration is of low quality. Finally, scores in the fourth domain, on treatment, could be improved if guidelines covered the psychological burden of lung cancer and if there was a pathway for psychological support services and supportive and palliative care. We discuss opportunities for improvement at the end of this country profile.

The Polish President signed a bill in January 2019 creating a legal framework for the development and adoption of a National Oncology Strategy for 2020-2030, to be updated every five years. This was in response to rising morbidity and mortality from cancer. A specific lung cancer strategy plan was published in 2017 by the Institute of Tuberculosis and Pulmonary Disease, Polish Group on Lung Cancer and Polish Cancer League. Overcoming the difference between the standard of care published in guidelines and the actual care delivered to patients is an important area for action in Poland. Workshop participants noted that lung cancer patients often receive fragmented care and long waiting periods between early symptoms and diagnosis.

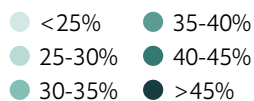
Summary scorecard



Poland

Lung cancer incidence

(Rate per 100,000, 2017)



Poland

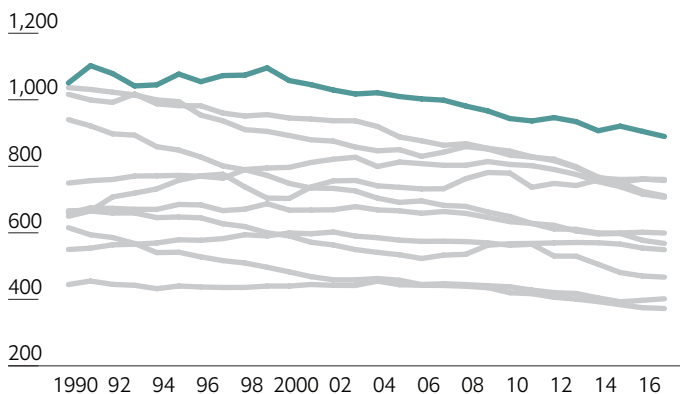
Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Poland	Europe	Global
Incidence	37	33	27
Prevalence	40	54	41
Mortality	39	27	24
Disability-Adjusted Life Years (DALYs)	890	628	503
Years Lived with Disability (YLDs)	8	8	7
Years of Life Lost (YLLs)	881	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

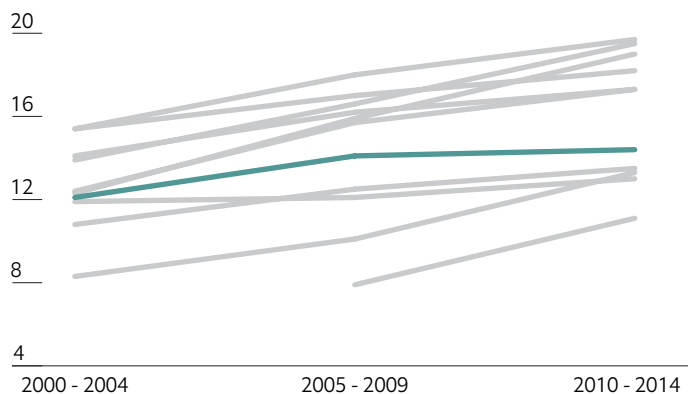
The costs of Tobacco

Tobacco costs the Polish economy 57,073 million zloty in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 71,600 deaths in Poland.²

Survival trend

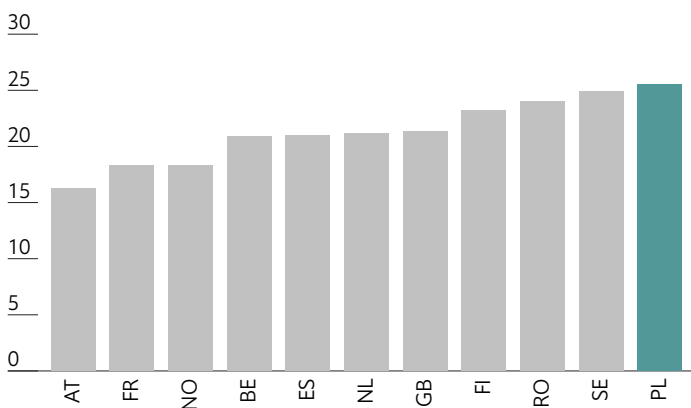
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

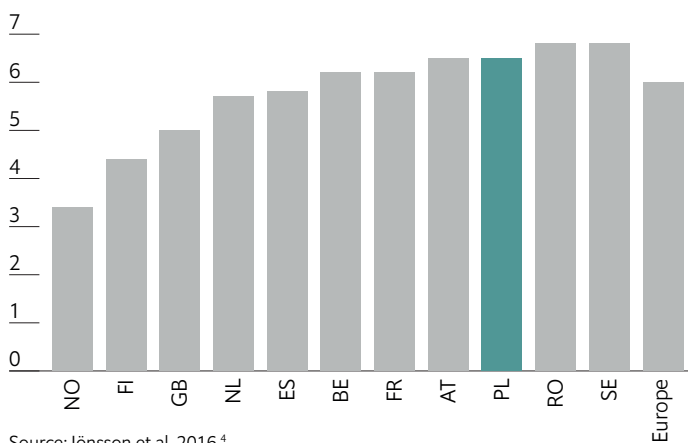
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator		Range	Score	Justification
Lung cancer is a strategic priority				
1	Operational, comprehensive, up to date national cancer control plan	0 – 5	3	<ul style="list-style-type: none"> ● Ministry of Health published an operational National Cancer Control Plan in 2005.⁶ ● In January 2019, the President signed a bill creating a legal framework for development and adoption of a National Cancer Strategy for 2020-2030 in response to rising morbidity and mortality from cancer. It will be updated every five years. The Minister of Health will present the strategy to the Council of Ministers by 30 September 2019.⁷ ● A specific lung cancer strategy plan was published by the Institute of Tuberculosis & Pulmonary Disease, Polish Group on Lung Cancer and Polish Cancer League in 2017. ● The NCCP is financed by state budget and auxiliary sources. ● The NCCP does not mention an implementation plan.
2	Comprehensive clinical guidelines for lung cancer	0 – 6	5	<ul style="list-style-type: none"> ● The Polish Society of Clinical Oncology published lung cancer clinical guidelines in 2019.⁸ ● Guidelines mention screening, diagnosis, treatment and supportive / palliative care. ● Patients with suspicious symptoms should have a chest CT. ● Guidelines do not discuss the process of shared decision making.
Lung cancer is a public health issue				
3	Tobacco control policies and public health measures	0 – 9	9	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁹ ● Poland is party to the World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● At least one national mass media campaign ran during the survey period (up to 2016). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● National smoke free legislation exists for indoor offices, restaurants/cafes/pubs/bars and public transportation.
4	E-cigarettes regulation and public health measures	0 – 4	4	<ul style="list-style-type: none"> ● E-cigarettes are classified as tobacco-related products and regulated by the Polish Anti-Tobacco Act (2016). Regulation requires specific reporting obligations on manufacturers and importers, and compliance with a range of product specifications including warnings on packages. ● Sale or distribution of e-cigarettes to people under 18 years is prohibited; duty free shops are exempt. ● Advertising, promotion and sponsorship related to e-cigarettes are banned. It is also prohibited to display items that imitate the packaging of e-cigarettes. ● Use of e-cigarettes in certain public places and on public transportation is prohibited.
5	National policies and programmes for environmental exposure control	0 – 2	1	<ul style="list-style-type: none"> ● Ministry of Environment Air Protection Department published National Program for Air Protection in 2015 and it runs through 2020. Air quality is determined by the content of pollutants, i.e. specific substances (gaseous or solid), which occur in the air in quantities greater than those required by the standards contained in the applicable regulations. ● A radon national action programme does not currently exist in Poland but plans to create one are in progress. The Council of Ministers has accepted a draft amendment on radon.
6	Evidence-based approach to lung cancer screening	0 – 1	0	<ul style="list-style-type: none"> ● No data found to show that Poland has conducted a lung cancer screening study or trial.
7	Patient organisations involvement in policy development	0 – 3	2	<ul style="list-style-type: none"> ● An independent lung cancer patient organisation exists in Poland; however, it was not involved in the lung cancer guideline development. Patient representatives are involved in the process of Health Technology Assessment (HTA).

Indicator	Range	Score	Justification
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	0	<ul style="list-style-type: none"> ● No mention of patients to be fast tracked in lung cancer clinical guidelines. ● No mention of a specific timeframe for diagnostic referral in suspected lung cancer patients.
9 Guidelines/ pathways for rapid referral to quality care	0 – 2	1	<ul style="list-style-type: none"> ● No mention of rapid referral for lung cancer patients to secondary/ tertiary care in lung cancer guidelines. ● Guidelines mention multidisciplinary teams guide treatment plans.
Lung cancer is at a crossroads			
10 Medical and surgical specialists	Number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2015: 4.21 pulmonologists 1.40 thoracic surgeons 15.48 general surgeons 5.7 oncologists.¹⁰
11 Radiotherapy accessibility	Number of MVM; % unmet need	unscored	<ul style="list-style-type: none"> ● -160 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -58.8%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	5	<ul style="list-style-type: none"> ● Histological and molecular testing is mentioned in lung cancer guidelines. ● EGFR and ALK are identified. ● EGFR, ALK and ROS1 approved and reimbursed. ● PD-L1 approved but not reimbursed, though anecdotally it may be reimbursed for patients treated with first and second line immunotherapy.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	0	<ul style="list-style-type: none"> ● Guidelines do not acknowledge psychological burden of lung cancer. ● No referral pathway to psychological support services is included in the guidelines for lung cancer.
15 Patient access to supportive / palliative care services	0 – 2	1	<ul style="list-style-type: none"> ● Guidelines do not include a referral pathway to supportive / palliative care services for lung cancer patients. ● Clinical oncologists have the option to specialise in palliative care. Anecdotally, supportive / palliative care knowledge is tested in final exams given to medical oncologists and radiation oncologists.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	4	<ul style="list-style-type: none"> ● High quality population-based cancer registry (regional) (2 points out of possible 3).¹¹ ● Low quality complete vital registration (2 points out of possible 4).¹¹
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 0.97% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 304.¹² ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.58.¹³

Opportunities for Improvement

Opportunity 1

Recommendation

- Poland needs an updated National Cancer Control Plan.

Rationale

- *Indicator 1: Poland's national cancer control plan was published in 2005 and needs to be updated; an update is currently in progress. The updated national cancer control plan should ideally include the following elements: discussion of prevention, screening and early detection, red flags and symptoms to look for in primary care, diagnosis, an implementation plan and a funding source.*

Opportunity 2

Recommendation

- Participation in lung cancer screening trials and studies may enable policymakers to determine whether screening is appropriate for its population.

Rationale

- *Indicator 6: We did not find any indication that Poland has conducted a lung cancer screening study or trial. However, while not meeting our criteria for this indicator, there has been a lung cancer early detection programme, initiated within the National Cancer Control Plan and financed by Ministry of Health in 2019.*

Opportunity 3

Recommendation

- Involvement of patient organisations in national assessments of disease and policy development can help to build consensus.

Rationale

- *Indicator 7: An independent lung cancer patient organisation exists in Poland, although there is no evidence that it was involved in the lung cancer guideline development. Involving patients in the development of clinical guidelines can 1) help to identify issues that may be overlooked by health professionals, 2) influence the development of recommendations from a patient and carer perspective, and 3) emphasise the importance of including shared decision making. Patient representatives in Poland, however, are involved in the process of Health Technology Assessment (HTA).*

Opportunity 4

Recommendation

- Referral for diagnostic assessment for patients suspected of having lung cancer should be prioritised within a specified time period as there is currently no mention of a rapid referral for diagnostic testing.

Rationale

- *Indicator 8 & 9: Providing a timeframe within which patients suspected of having lung cancer should receive testing is an important milestone for delivery of care as well as having a timeframe for confirmed lung cancer patients to receive secondary or tertiary care. Poland does not provide such timeframes, nor does it have dedicated fast track referral processes in its lung cancer guidelines. Workshop participants emphasised the need to decrease the time from a patient's early onset of symptoms to receiving a diagnosis.*

Opportunity 5

Recommendation

- Ensure that the psychological burden faced by lung cancer patients is addressed with pathways to access psychological support services. Supportive and palliative care should be included in the lung cancer guidelines.

Rationale

- *Indicator 14 & 15: Poland neither includes psychological assessment nor mentions the psychological burden of lung cancer in their lung cancer guidelines. Additionally, there is no referral pathway for either psychological support or supportive and palliative care services.*

Opportunity 6

Recommendation

- Cancer registries lack clinical data. In Poland, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Poland's cancer registry has been evaluated to be at a high quality at a regional basis (though not at a national base), while its vital registration data collection systems have been evaluated as being of low quality. The system in Poland needs improvement. Additionally, clinicians have suggested that a stronger clinical component to the cancer registry—including stage at diagnosis and pathology data—could help to improve the overall care that lung cancer patients receive. Workshop participants noted that there is a lack of adequate knowledge about new treatments for lung cancer in Poland, and that having an operational clinical cancer registry can help to collect and synthesise up-to-date evidence of the impact of emerging therapies.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

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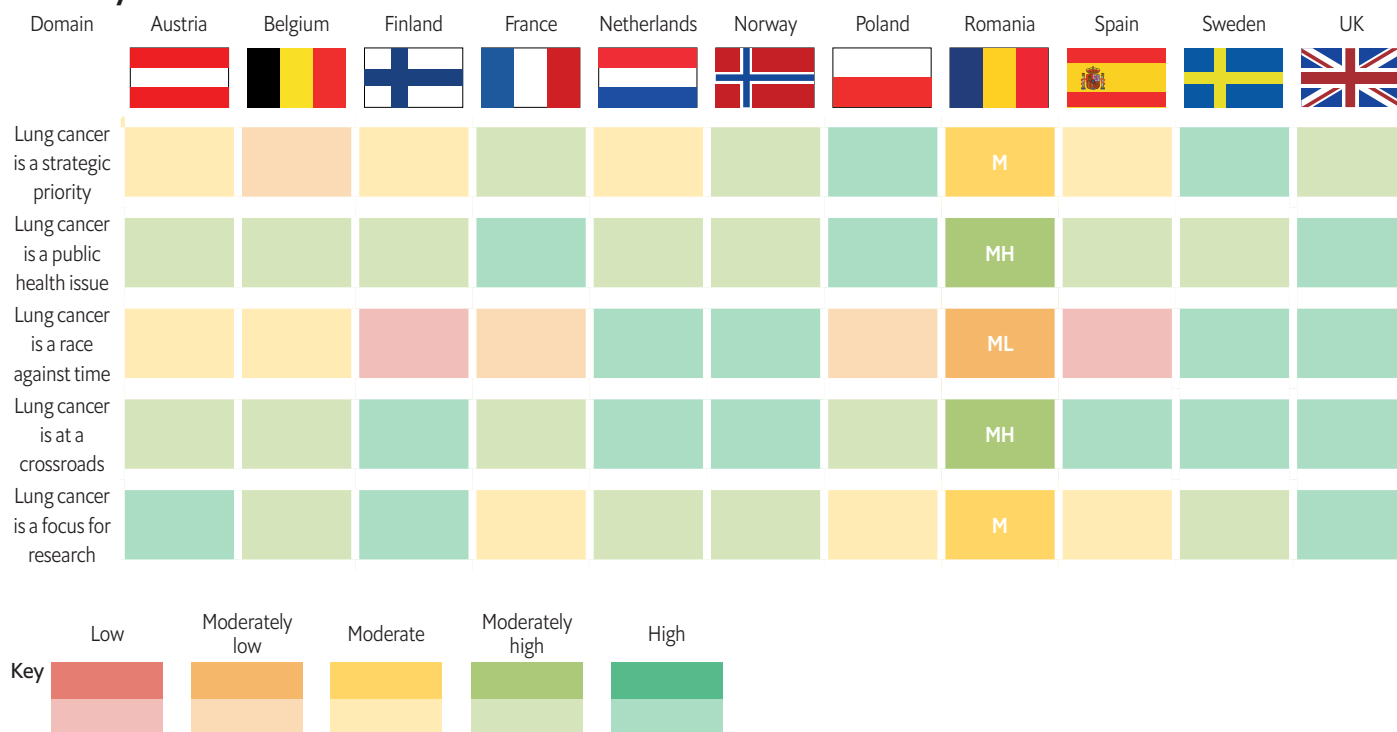


Romania: Lung Cancer Country Profile

Romania has middling scores across all five of the domains, though it scores moderately well in the public health (second) and treatment (fourth) domains. Romania performs at a moderately low level in the first domain, however, because it has neither a National Cancer Control Plan nor a lung cancer specific control plan. Also the lung cancer clinical guidelines do not include a discussion on shared decision making or supportive and palliative care. The country also performs at a moderately low level in the third domain because guidelines neither have timeframes nor fast-tracking for diagnostic testing, nor is there a rapid referral pathway to secondary or tertiary care. Scores are also only moderate in the fifth domain because the cancer registry is not highly rated. We discuss opportunities for improvement at the end of this country profile.

Awareness of lung cancer and the challenges it poses to Romanians is increasing at the governmental level. The country is currently working on a National Cancer Control Plan, which will help to ensure a co-ordinated approach for oncology services. Addressing the challenges at all points from prevention, screening, early detection, symptoms to look for in primary care, diagnosis, and improving access to treatment will be important goals for the new plan. Workshop participants emphasised that understanding how to develop focused early detection programmes and improving access to the latest treatments are two important elements in improving outcomes for patients.

Summary scorecard



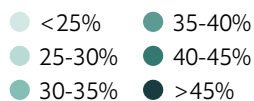
Sponsored by



Romania

Lung cancer incidence

(Rate per 100,000, 2017)



Romania

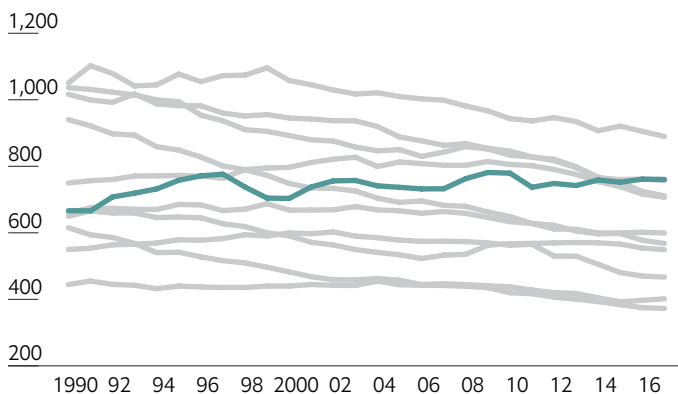
Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Romania	Europe	Global
Incidence	30	33	27
Prevalence	32	54	41
Mortality	30	27	24
Disability-Adjusted Life Years (DALYs)	760	628	503
Years Lived with Disability (YLDs)	7	8	7
Years of Life Lost (YLLs)	754	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



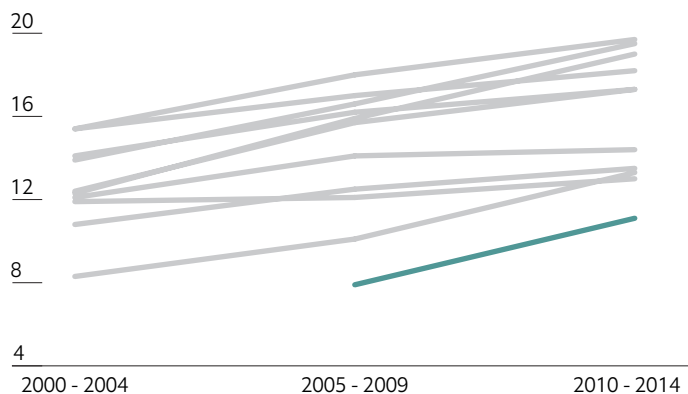
Source: Global Burden of Disease, 2017.¹

The costs of Tobacco

Tobacco costs the economy 24,704 million new leu in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.² Every year, tobacco-related diseases cause more than 36,600 deaths in Romania.²

Survival trend

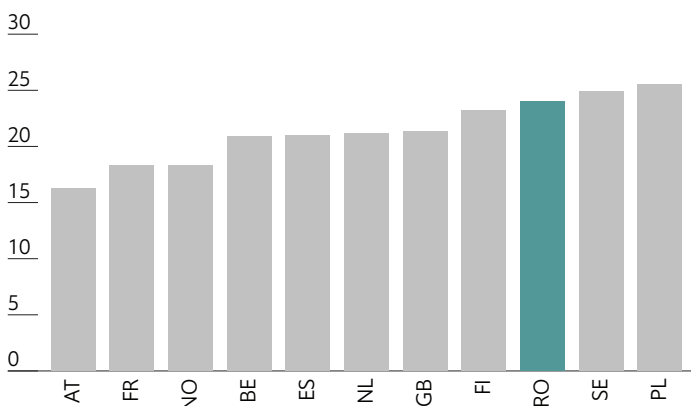
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

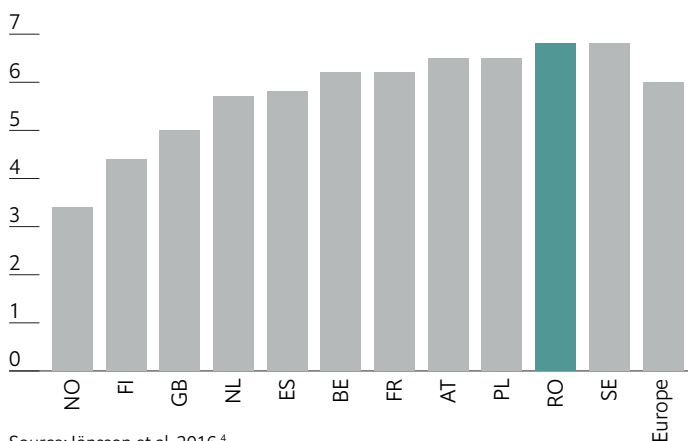
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator		Range	Score	Justification
Lung cancer is a strategic priority				
1	Operational, comprehensive, up to date national cancer control plan	0 – 5	0	<ul style="list-style-type: none"> ● Romania does not have a National Cancer Control Plan. There is a National Health Strategy, 2014-2020, but this is not a national cancer control plan. ● A specific lung cancer control plan has not been published by the government or health ministry.
2	Comprehensive clinical guidelines for lung cancer	0 – 6	6	<ul style="list-style-type: none"> ● Lung cancer clinical guidelines were published jointly by the Society of Medical Oncology, Society of Thoracic Surgery, Romanian Society of Radiotherapy and Medical Oncology, Romanian Society of Pneumology, Section of Pulmonary Cancer and Section of Broncology in 2015.⁶ ● The guidelines mention screening but no particular method is endorsed. ● Guidelines cover diagnosis, treatment, supportive / palliative care and shared decision making.
Lung cancer is a public health issue				
3	Tobacco control policies and public health measures	0 – 9	9	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁷ ● Romania is party to World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● At least one national mass media campaign ran during the survey period (up to 2016). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● National smoke free legislation exists for indoor offices, restaurants/ cafes/pubs/bars and public transportation.
4	E-cigarettes regulation and public health measures	0 – 4	2	<ul style="list-style-type: none"> ● E-cigarettes are regulated by law. ● The law restricts advertising, promotion and sponsorship related to e-cigarettes. ● No clear evidence to suggest that the sale of e-cigarettes is subject to age restrictions. ● E-cigarettes are only banned on public transport.
5	National policies and programmes for environmental exposure control	0 – 2	2	<ul style="list-style-type: none"> ● Air quality strategy mentioned within the general National Strategy of Romania on Climate Change, 2013-2020. ● A radon control programme has been published by the Romanian Government.
6	Evidence-based approach to lung cancer screening	0 – 1	0	<ul style="list-style-type: none"> ● No data found to show that Romania has conducted a lung cancer screening study or trial.
7	Patient organisations involvement in policy development	0 – 3	1	<ul style="list-style-type: none"> ● A specific lung cancer patient organisation has not been identified in Romania. ● No clear evidence to suggest that patients were represented in clinical guideline development. ● Civil society has the opportunity to comment on HTA recommendations
Lung cancer is a race against time				
8	Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	0	<ul style="list-style-type: none"> ● No mention of patients to be fast-tracked in lung cancer clinical guidelines. However, the guidelines mention that an immediate chest x-ray is to be done if red flag symptoms are present. ● No mention of a specific timeframe for diagnostic referral in suspected lung cancer patients.
9	Guidelines / pathways for rapid referral to quality care	0 – 2	1	<ul style="list-style-type: none"> ● No mention of rapid referral for lung cancer patients to secondary / tertiary care. ● Lung cancer guidelines recommend rapid referral for radiography, stating that pulmonary radiographs should be accessible to the family doctor as soon as possible. ● Multidisciplinary team mentioned to guide treatment plan in lung cancer guidelines. Guidelines recognise importance of the involvement of a multidisciplinary team in improving lung cancer prognosis.

Indicator		Range	Score	Justification
Lung cancer is at a crossroads				
10	Medical and surgical specialists	number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2015: 5.70 pulmonologists 1.60 thoracic surgeons 12.83 general surgeons 3.1 oncologists.⁸
11	Radiotherapy accessibility	unmet need	unscored	<ul style="list-style-type: none"> ● -77 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -77%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12	Tumour testing recommendations and accessibility	0 – 6	3	<ul style="list-style-type: none"> ● Lung cancer guidelines mention molecular testing. ● Specific markers are identified: EGFR and ALK. ● EGFR approved and reimbursed. ALK, ROS1 and PD-L1 approved but not reimbursed.
13	Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14	Understanding psychological burden of lung cancer and access to support services	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not include psychological assessment or mention the psychological burden of lung cancer. ● There is no referral pathway to psychological support services in lung cancer guidelines.
15	Patient access to supportive / palliative care services	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not mention a referral pathway to supportive / palliative care services. ● Guidelines recommend that early initiation of palliative care be provided in parallel with standard oncological therapy. ● There is no evidence to demonstrate that oncologists in Romania have training in supportive / palliative care.
Lung cancer is a focus for research				
16	Clinical and outcomes data collection	0 – 7	5	<ul style="list-style-type: none"> ● Population-based cancer registry (PBCR national or regional) (1 point out of a possible 3).⁹ ● High quality complete vital registration (4 points out of a possible 4).⁹
17	Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 0.48% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 147.¹⁰ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.69.¹¹

Opportunities for Improvement

Opportunity 1

Recommendation

- Romania needs to publish a National Cancer Control Plan.

Rationale

- *Indicator 1: Romania does not have a National Cancer Control Plan. It has a National Health Strategy 2014-2020, but this is not a national cancer control plan. A national cancer control plan should ideally include the following elements: discussion of prevention, screening and early detection, red flags and symptoms to look for in primary care, diagnosis, an implementation plan and a funding source. A specific lung cancer control plan has also not been published by the government or health ministry.*

Opportunity 2

Recommendation

- Participation in lung cancer screening trials and studies may enable Romania to determine whether screening is appropriate for its population.

Rationale

- *Indicators 6 & 17: There is no evidence to show that Romania has participated in a lung cancer screening study or clinical trial. Workshop participants felt that this is an important area to be addressed in Romania as involvement in scientific research can improve patient access to new treatments.*

Opportunity 3

Recommendation

- Involvement of patient organisations in national assessments of disease and policy development can help to build consensus.

Rationale

- *Indicator 7: A specific lung cancer patient organisation has not been identified in Romania. Therefore we have no evidence that patients were represented in clinical guideline development. Involving patients in the development of clinical guidelines can 1) help to identify issues that may be overlooked by health professionals, 2) influence the development of recommendations from a patient and carer perspective, and 3) emphasise the importance of including shared decision making.*

Opportunity 4

Recommendation

- Referral for diagnostic assessment for patients suspected of having lung cancer should be prioritised within a specified time period as there is currently no mention of a rapid referral for diagnostic testing.

Rationale

- *Indicators 8 & 9: Providing a timeframe within which patients suspected of having lung cancer should receive testing is an important milestone for delivery of care as well as having a timeframe for confirmed lung cancer patients to receive secondary or tertiary care. Romania does not provide such timeframes, nor does it have dedicated fast-track referral processes in its lung cancer guidelines. Workshop participants emphasised the need to decrease the time from a patient's early onset of symptoms to receiving a diagnosis.*

Opportunity 5

Recommendation

- Improved diagnostic testing (including increased capacity) is needed for people suspected of having lung cancer.

Rationale

- *Indicator 8: Streamlining the time to diagnosis through improved diagnostic testing will improve the ability of people diagnosed with lung cancer to move more swiftly into treatment. Workshop participants called for a coherent programme to provide tests that are cost efficient and offered within an organised programme to assist clinicians, who are often overloaded.*

Opportunity 6

Recommendation

- Ensure that the psychological burden faced by lung cancer patients is addressed with pathways to access psychological support services. Supportive and palliative care should be included in the lung cancer guidelines.

Rationale

- *Indicators 14 & 15: Romania neither includes psychological assessment nor mentions the psychological burden of lung cancer in their lung cancer guidelines. While the guidelines recommend that early initiation of palliative care be provided in parallel with standard oncological therapy, no referral pathway is provided. There is also no evidence that oncologists in Romania receive formal training in supportive and palliative care.*

Opportunity 7

Recommendation

- Cancer registries lack clinical data. In Romania, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Romania has a cancer registry but it does not score well, although the complete vital registration system has been evaluated as being of high quality. The population-based cancer registry needs to be modernised to improve access to information. Additionally, clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. Workshop participants wanted to see improvements in the quality of the cancer registry to ensure it provides sufficient information to support budgetary decision making.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

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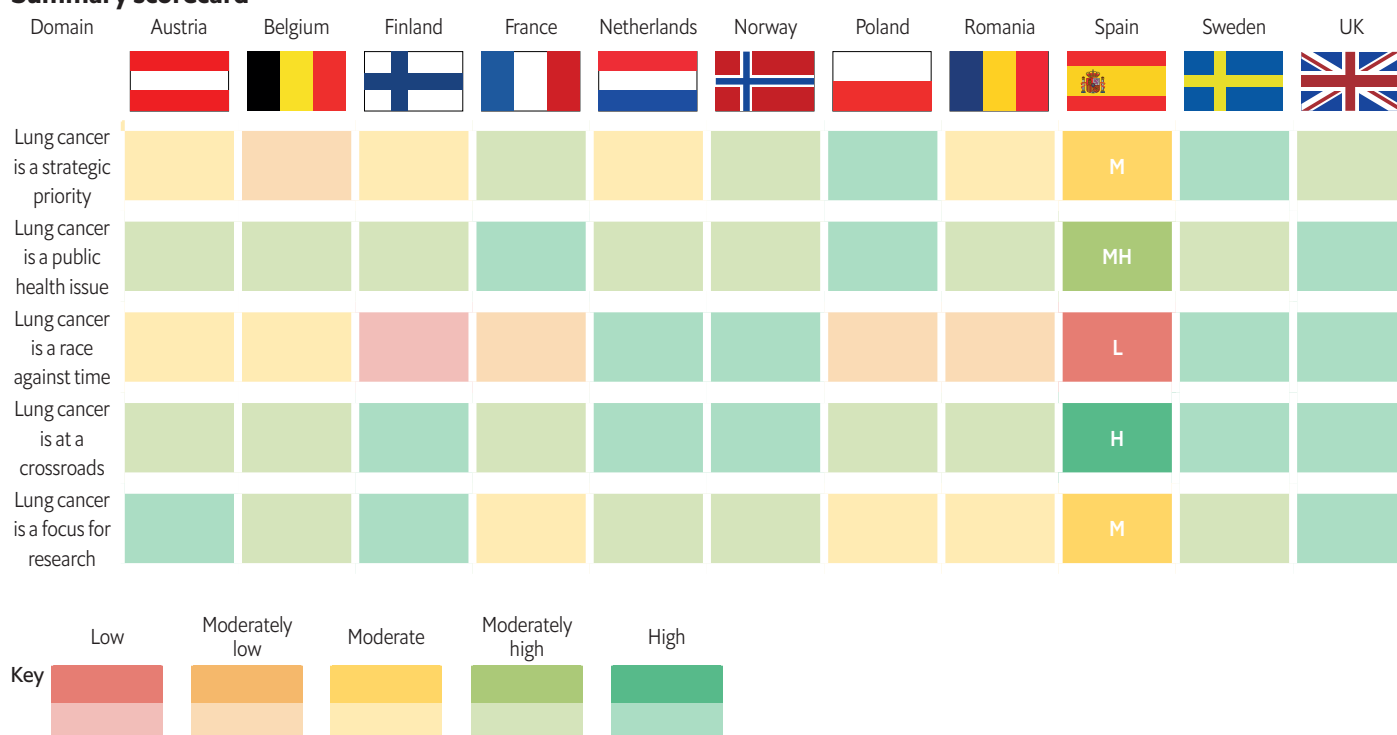
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Spain: Lung Cancer Country Profile

Spain performs only moderately across the scorecard: its best performance is in the fourth domain, while it performs particularly poorly in the third domain—focussing on diagnosis. This poor performance is because the guidelines present neither timeframes nor fast-tracking for diagnostic testing, nor a rapid referral pathway to secondary or tertiary care. Scores in the first domain, on strategy, could be improved by the inclusion of a specific lung cancer control plan and details of the funding of the ‘National Cancer Strategy’ (although this is challenging because regions have their own systems). Also, guidelines mention neither screening nor shared decision making. Moderately high performance in the public health domain is due to a lack of an evidence based approach to screening and the absence of lung cancer patient organisations’ involvement in guideline development and HTAs. Finally, middling performance in the fifth domain is because Spain’s cancer registry receives a high score only on a regional, not a national basis, and the complete vital registration component is of medium quality. We discuss opportunities for improvement at the end of this country profile.

Obtaining national-level information or consensus is challenging because the Spanish health system is devolved to regions. Plans written at the national level are reinterpreted at regional levels and further reinterpreted at the hospital level. A unified national approach via a national cancer control plan may help ensure equitable access. Workshop participants noted that one of the main challenges for their healthcare system is building strong relationships between primary care and hospital-based specialists.

Summary scorecard



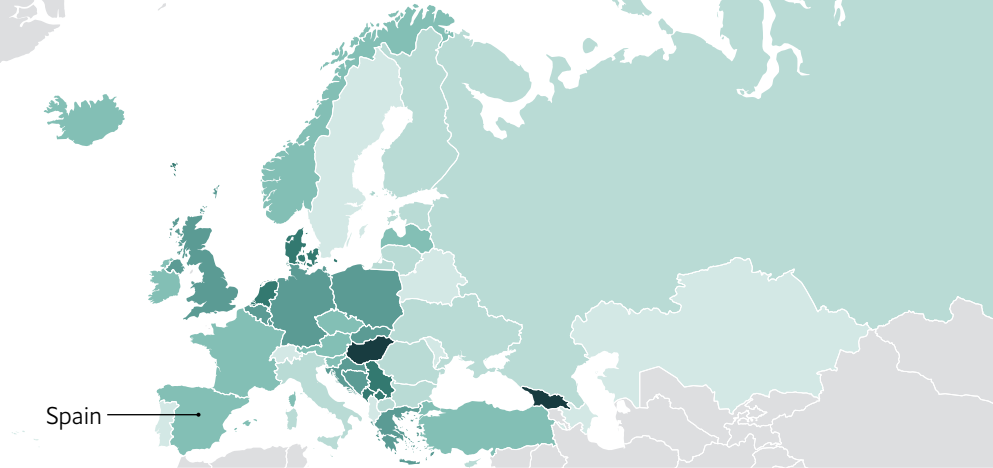
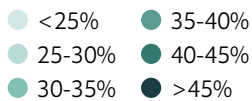
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Spain

Lung cancer incidence

(Rate per 100,000, 2017)



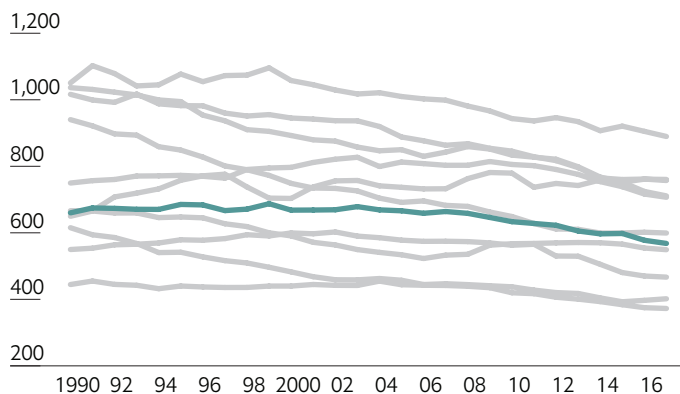
Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Spain	Europe	Global
Incidence	33	33	27
Prevalence	67	54	41
Mortality	25	27	24
Disability-Adjusted Life Years (DALYs)	568	628	503
Years Lived with Disability (YLDs)	9	8	7
Years of Life Lost (YLLs)	559	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



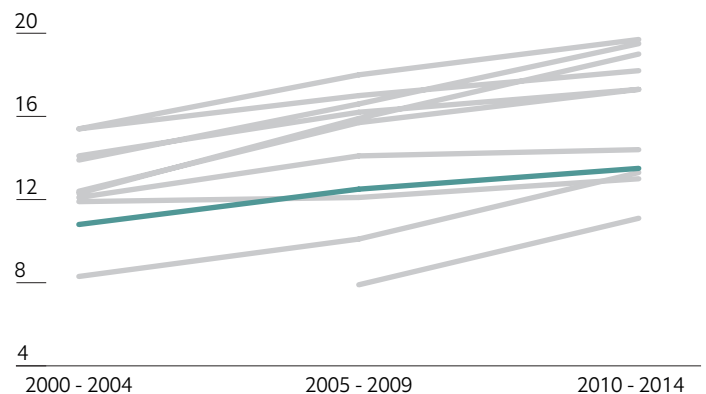
Source: Global Burden of Disease, 2017.¹

The costs of Tobacco

Tobacco costs the economy €20,773 million in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.² Every year, tobacco-related diseases cause more than 57,200 deaths in Spain.²

Survival trend

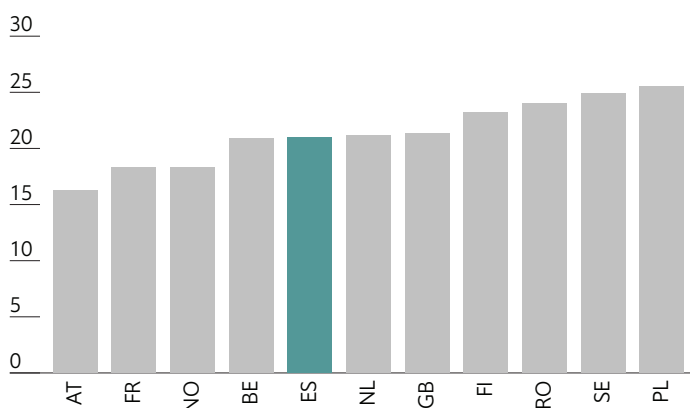
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

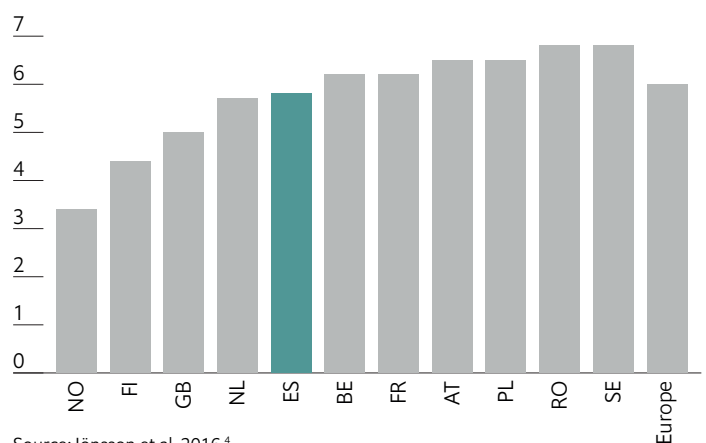
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator		Range	Score	Justification
Lung cancer is a strategic priority				
1	Operational, comprehensive, up-to-date national cancer control plan	0 – 5	2	<ul style="list-style-type: none"> ● The Ministry of Health, Social Services and Equality published a Cancer Strategy of the Spanish National Health System in 2010.⁶ ● The National Cancer Strategy includes implementation within the monitoring and evaluation section of the plan. ● No funds are officially allocated in the National Cancer Strategy. The strategy consists of recommendations. Each region has a specific financing system. ● A specific lung cancer control plan has not been published by the government or health ministry.
2	Comprehensive clinical guidelines for lung cancer	0 – 6	4	<ul style="list-style-type: none"> ● The Spanish Society of Medical Oncology published lung cancer guidelines in 2018.⁷ ● The guidelines cover diagnosis, treatment, supportive / palliative care and strongly recommend early palliative care. ● The guidelines do not mention screening or shared decision-making.
Lung cancer is a public health issue				
3	Tobacco control policies and public health measures	0 – 9	8	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁸ ● Spain is party to World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● National smoke-free legislation exists for indoor offices, restaurants/cafes/ pubs/bars and public transportation. ● There was no national mass media campaign during the survey period (up to 2016).
4	E-cigarettes regulation and public health measures	0 – 4	2	<ul style="list-style-type: none"> ● Safety and quality standards for e-cigarette regulation are in place. ● The sale of e-cigarettes is not expressly prohibited for people under 18 years of age. The packaging is mandated to contain a leaflet that states “the product is not recommended for use by young people and non-smokers, a recommendation to keep the product out of the reach of children.” ● Advertising and promotion is prohibited. ● There is no information on whether or where the use of e-cigarettes is banned.
5	National policies and programmes for environmental exposure control	0 – 2	1	<ul style="list-style-type: none"> ● Spain has a National Air Quality and Atmospheric Protection Plan, 2013-2016. ● Spain does not have a national radon control plan.
6	Evidence-based approach to lung cancer screening	0 – 1	0	<ul style="list-style-type: none"> ● No data found to show that Spain has conducted a lung cancer screening study or trial.
7	Patient organisations involvement in policy development	0 – 3	1	<ul style="list-style-type: none"> ● Lung cancer patient organisation exists in Spain. ● No clear evidence to suggest that patients were represented in clinical guideline development. ● There is no process to involve civil society in Health Technology Assessments (HTAs).
Lung cancer is a race against time				
8	Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	0	<ul style="list-style-type: none"> ● No mention of patients to be fast-tracked in lung cancer clinical guidelines. ● No mention of a specific timeframe for diagnostic referral in suspected lung cancer patients. ● There is some anecdotal evidence to suggest that pathways may exist and that patients may be fast-tracked in regional and local hospital settings.
9	Guidelines / pathways for rapid referral to quality care	0 – 2	0	<ul style="list-style-type: none"> ● No mention of rapid referral for lung cancer patients to secondary / tertiary care. ● The guidelines do not mention multidisciplinary teams. Multidisciplinary cancer care models are discussed in the National Cancer Strategy 2009.

Indicator		Range	Score	Justification
Lung cancer is at a crossroads				
10	Medical and surgical specialists	Number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2015 5.47 pulmonologists 1.78 thoracic surgeons 11.39 general surgeons 3.9 oncologists.⁹
11	Radiotherapy accessibility	Number of MVM; % unmet need	unscored	<ul style="list-style-type: none"> ● -134 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -35.8%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12	Tumour testing recommendations and accessibility	0 – 6	6	<ul style="list-style-type: none"> ● Histological and molecular testing is mentioned in the guidelines. ● Specific markers are identified: EGFR, ALK and ROS1 are specifically identified in the lung cancer guidelines. ● Tests are reimbursed and approved: EGFR, ALK, ROS1 and PD-L1.
13	Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14	Understanding psychological burden of lung cancer and access to support services	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not include psychological assessment or mention the psychological burden of lung cancer. ● No referral pathway to psychological support services in lung cancer guidelines.
15	Patient access to supportive / palliative care services	0 – 2	1	<ul style="list-style-type: none"> ● No referral pathway mentioned in lung cancer guidelines. ● Palliative care training is part of the undergraduate education curriculum in medical schools in Spain.
Lung cancer is a focus for research				
16	Clinical and outcomes data collection	0 – 7	5	<ul style="list-style-type: none"> ● High quality population-based cancer registry (PBCR) (regional) (2 points out of a possible 3).¹⁰ ● Medium quality complete vital registration (3 points out of a possible 4).¹⁰
17	Research support and funding	R&D as % of GDP; ratio of clinical trials	Unscored	<ul style="list-style-type: none"> ● 1.19% of GDP spent on research & development in 2016. ● Number of clinical trials between 2009-2018 = 595.¹¹ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.45.¹²

Opportunities for Improvement

Opportunity 1

Recommendation

- Spain needs an updated National Cancer Control Plan.

Rationale

- *Indicator 1: Spain's National Cancer Control plan was published in 2010 and needs to be updated. There is a decentralised approach to the delivery of cancer care in Spain and the regions are responsible for the care that cancer patients receive. However, having a unified national approach via a national cancer control plan will help ensure equitable access and that economically deprived areas are not disadvantaged. Workshop participants noted that the National Cancer Strategy is currently being updated. The new strategy will be implemented at three different levels: national, regional and hospital. Participants suggested that implementing quality standards or an accreditation system could help to address the local and regional variations in Spain.*

Opportunity 2

Recommendation

- Participation in lung cancer screening trials and studies may enable Spain to determine whether screening is appropriate for its population.

Rationale

- *Indicator 6: There is no evidence to show that Spain has participated in a lung cancer screening study or clinical trial. Workshop participants felt strongly that screening should be part of the National Cancer Strategy.*

Opportunity 3

Recommendation

- Involvement of patient organisations in national assessments of disease and policy development can help to build consensus.

Rationale

- *Indicator 7: A specific lung cancer patient organisation exists in Spain. However, there is no clear evidence that patients were represented in clinical guideline development. Involving patients in the development of clinical guidelines can 1) help to identify issues that may be overlooked by health professionals, 2) influence the development of recommendations from a patient and carer perspective, and 3) emphasise the importance of including shared decision making. Workshop participants noted some concern as to whether lung cancer patient organisations were 'ready' to participate in the development of clinical guidelines. Perhaps reassuring organisations that they would be participating in order to ensure their experiences are represented (rather than being expected to contribute opinions on scientific issues) could help to allay their concerns.*

Opportunity 4

Recommendation

- Referral for diagnostic assessment for patients suspected of having lung cancer should be prioritised within a specified time period as there is currently no mention of a rapid referral for diagnostic testing.

Rationale

- *Indicators 8 & 9: Providing a timeframe within which patients suspected of having lung cancer should receive testing is an important milestone for delivery of care, as well as having a timeframe for confirmed lung cancer patients to receive secondary or tertiary care. Spain does not provide such timeframes, nor does it have dedicated fast-track referral processes in its lung cancer guidelines. Workshop participants noted the importance of building strong relationships between primary care and hospital-based specialists. Understanding the reasons for delay in diagnostic assessment is needed in order to implement appropriate measures for improvement.*

Opportunity 5

Recommendation

- Ensure that the psychological burden faced by lung cancer patients is addressed with pathways to access psychological support services. Supportive and palliative care should be included in the lung cancer guidelines.

Rationale

- *Indicators 14 & 15: Spain neither includes psychological assessment nor mentions the psychological burden of lung cancer in their lung cancer guidelines. Additionally, there is no referral pathway for either psychological support or supportive and palliative care services. Workshop participants noted that while cancer-focussed psychological services work well in some hospitals, there is variation between regions. Some variation is due to differences in reimbursement for psychological support services, which has limited the way in which they have been integrated into patient care. Patient organisations strongly support a uniform delivery of psychological assistance for cancer patients. Workshop participants noted that a well-defined national palliative care strategy exists in Spain but it is not specifically detailed for lung cancer.*

Opportunity 6

Recommendation

- Cancer registries lack clinical data. In Spain, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Spain's cancer registry has been evaluated to be at a high quality at a regional basis (though not at a national base), while its vital registration data collection systems have been evaluated as being of medium quality. Additionally, clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. Workshop participants noted that the most important challenge is to link electronic data in clinical records with population-based cancer registries.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

The focus of the research programme is not to rank countries but rather to identify opportunities to improve patient outcomes in each country.

See the regional paper for the full methodology.

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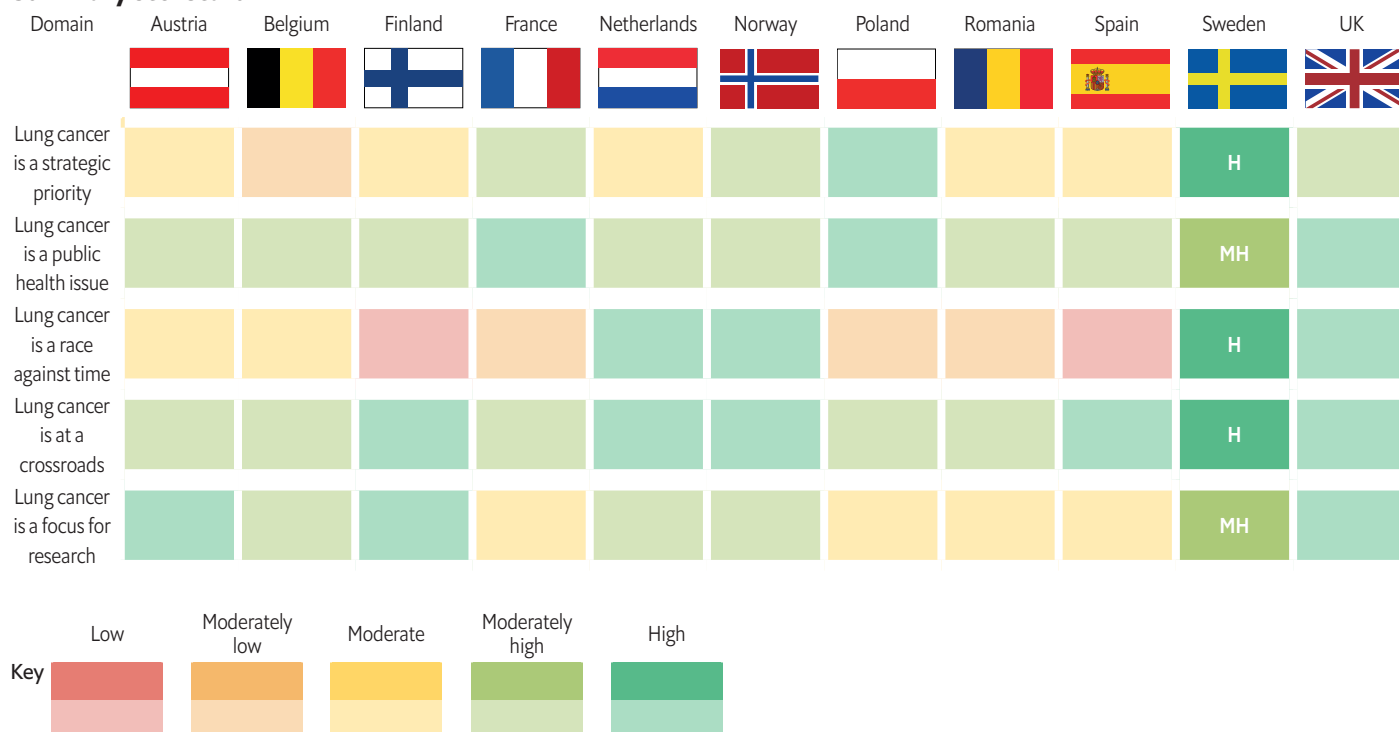


Sweden: Lung Cancer Country Profile

Sweden performs strongly across all five domains, scoring 'high' throughout except for the second and fifth domains where it scores 'moderately high'. High scores are due to having comprehensive guidelines incorporating fast-tracking suspected patients with timeframes for diagnostic referral, rapid referral to treatment, good use of histological testing and availability of treatment and referral pathways for supportive and palliative care. The second domain scores slightly lower due to no evidence based approaches to screening and not having patient organisations involved in HTAs. While scoring well overall, there are some things Sweden can do to improve scores, including the development of a lung cancer specific control plan, ensuring greater involvement of lung cancer patient organisations and improving smoking cessation programmes. We discuss opportunities for improvement at the end of this country profile.

Implementation of the National Cancer Control Plan in 2009 led to the establishment of regional cancer centres. While funding is provided by the Swedish government, the government is not responsible for healthcare. Rather, there is a decentralised approach and county councils are responsible for the delivery of care. Consequently, each regional cancer centre has its own cancer control plan. Nevertheless, a unified national approach via a national cancer control plan may help to ensure equity of provision, and in June 2019 the Government announced an investment of half a billion SEK on cancer care. Workshop participants reported that the National Board of Health and Welfare is currently investigating how a lung cancer screening programme can be implemented in Sweden. Also discussed was regional variation in care: for example, there is significant variation between the country's 21 regions in referral timelines from primary to specialised care.

Summary scorecard



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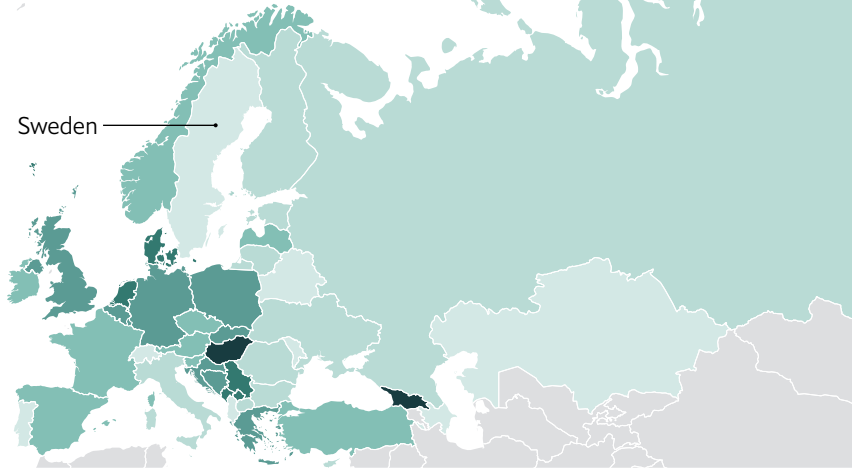
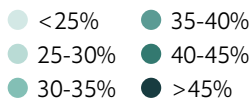


Sweden

Sweden

Lung cancer incidence

(Rate per 100,000, 2017)



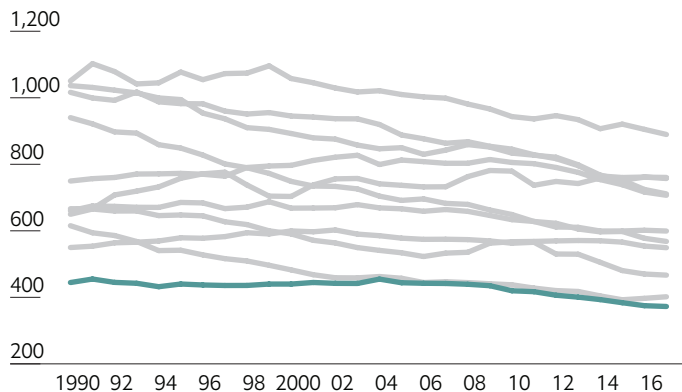
Lung cancer in numbers

Lung cancer statistics Rate per 100,000, 2017	Sweden	Europe	Global
Incidence	21	33	27
Prevalence	32	54	41
Mortality	19	27	24
Disability-Adjusted Life Years (DALYs)	373	628	503
Years Lived with Disability (YLDs)	5	8	7
Years of Life Lost (YLLs)	367	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

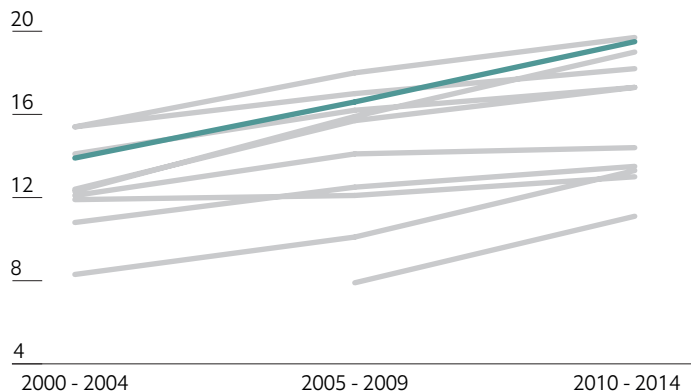
The costs of Tobacco

Tobacco costs the Swedish economy 38,354 million krona in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 10,400 deaths in Sweden.²

Survival trend

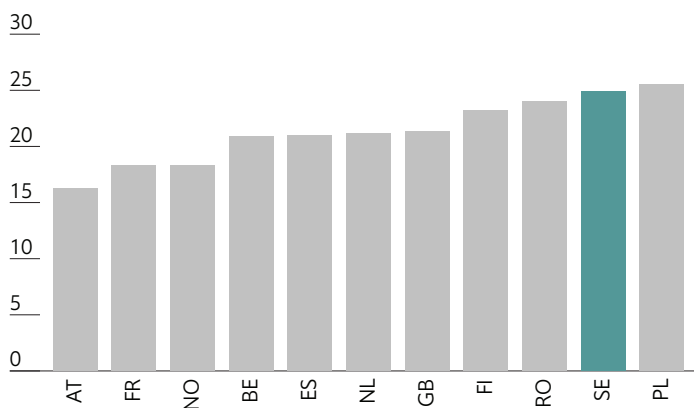
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

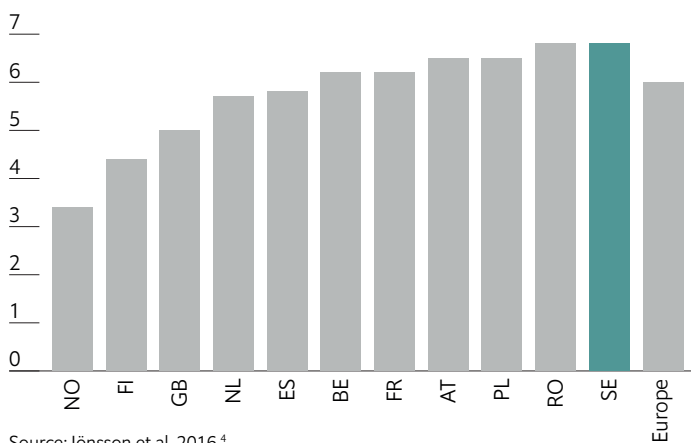
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator	Range	Score	Justification
Lung cancer is a strategic priority			
1 Operational, comprehensive, up to date national cancer control plan	0 – 5	4	<ul style="list-style-type: none"> ● The Ministry of Social Affairs published an operational National Cancer Control Plan in 2009.⁶ In 2018, the government published a report presenting the long-term plan for cancer care until 2025 and beyond. ● The implementation of the 2009 plan resulted in the establishment of regional cancer centres resulting in a decentralised delivery of cancer care which is the responsibility of county councils. ● The 2009 plan identified central government grants as the source of funding. Budgets are allocated to cancer centres and county councils who are responsible for implementing the cancer strategy within the county. ● A specific lung cancer control plan has not been published by the government or health ministry.
2 Comprehensive clinical guidelines for lung cancer	0 – 6	6	<ul style="list-style-type: none"> ● Lung cancer clinical guidelines were published by the Regional Cancer Centre and Planning Group for Lung Cancer in 2018.⁷ ● Guidelines mention screening and cover diagnosis, treatment and supportive / palliative care. ● The 2018 standardised pathway for lung cancer covers shared decision-making.
Lung cancer is a public health issue			
3 Tobacco control policies and public health measures	0 – 9	8	<ul style="list-style-type: none"> ● Government objectives on tobacco control and a national agency for tobacco control exists.⁸ ● Advertising is banned on national TV and radio. ● The law mandates that health warnings appear on tobacco packages. ● Sweden is party to World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● National smoke-free legislation exists for indoor offices, restaurants/cafes/pubs/bars and public transportation. ● No national mass media campaign ran during the survey period (up to 2016).
4 E-cigarettes regulation and public health measures	0 – 4	3	<ul style="list-style-type: none"> ● Laws regulate the safety and quality standards of e-cigarettes. ● Sales of e-cigarettes are prohibited to people under 18 years of age. ● There are restrictions on advertising, promotion and sponsorships. ● E-cigarette usage is not banned: vaping in Sweden is permitted where tobacco smoking is permitted.
5 National policies and programmes for environmental exposure control	0 – 2	2	<ul style="list-style-type: none"> ● Air quality is covered under the Clean Air Strategy (2015) and Climate and Air Quality Policy (2014-2018). ● A Swedish action plan for reducing the health effects of radon was published in 2018.
6 Evidence-based approach to lung cancer screening	0 – 1	0	<ul style="list-style-type: none"> ● No data found to show that Sweden has conducted a lung cancer screening study or trial.
7 Patient organisations involvement in policy development	0 – 3	2	<ul style="list-style-type: none"> ● Lung cancer guidelines and care plan involved patients during development. ● Civil society has no opportunity to comment on Health Technology Assessment (HTA) recommendations.
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	2	<ul style="list-style-type: none"> ● The standardised care pathway for lung cancer mention fast-tracking and specific timeframe for diagnostic referral in suspected lung cancer patients.
9 Guidelines/ pathways for rapid referral to quality care	0 – 2	2	<ul style="list-style-type: none"> ● The standardised care pathway for lung cancer provides timeframes and process for referral to care. ● Guidelines discuss care delivery with multidisciplinary teams.

Indicator	Range	Score	Justification
Lung cancer is at a crossroads			
10 Medical and surgical specialists	number per 100,000	unscored	<ul style="list-style-type: none"> ● In 2014: 2.12 pulmonologists 1.39 thoracic surgeons 16.10 general surgeons 5.7 oncologists.⁹
11 Radiotherapy accessibility	unmet need	unscored	<ul style="list-style-type: none"> ● -13 = the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit) ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -14.6%. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	6	<ul style="list-style-type: none"> ● The lung cancer guidelines mention molecular testing. ● Specific markers are identified: EGFR, ALK, ROS1 and PD-L1. ● Tests are approved and reimbursed: EGFR, ALK, ROS1 and PD-L1.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines include psychological assessment and/or mention the psychological burden of lung cancer. ● Lung cancer guidelines mention a referral pathway to psychological support services.
15 Patient access to supportive / palliative care services	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines mention a referral pathway to supportive / palliative care services. ● Oncologists receive training in supportive / palliative care.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	6	<ul style="list-style-type: none"> ● High quality national population-based cancer registry (3 points out of a possible 3).¹⁰ ● Medium quality complete vital registration (3 points out of a possible 4).¹⁰
17 Research support and funding	R&D as % of GDP; ratio of clinical trials	unscored	<ul style="list-style-type: none"> ● 3.25% of GDP spent on research and development in 2016. ● Number of clinical trials between 2009-2018 = 115.¹¹ ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.21.¹²

Opportunities for Improvement

Opportunity 1

Recommendation

- Sweden needs an updated National Cancer Control Plan.

Rationale

- *Indicator 1: Following the publication of the National Cancer Control Plan in 2009, regional cancer centres were established. While funding is provided by the Swedish government, the government is not responsible for healthcare. Rather, there is a decentralised approach, and county councils are responsible for the delivery of care. This leads to a competition among the regions, yet workshop participants felt that regions need to instead collaborate with each other. While regional cancer centres have their own plans, a national approach—via a national cancer control plan—may help to ensure that everyone has access to similar standards of care and that economically deprived areas are not disadvantaged. Participants suggested that the plan needs to address regional referral lead time variation from primary to specialised care.*

Opportunity 2

Recommendation

- Participation in lung cancer screening trials or studies may enable Sweden to determine whether screening is appropriate for its population.

Rationale

- *Indicator 6: There is no evidence to show that Sweden has participated in a lung cancer screening study or clinical trial. However, workshop participants did not believe it is necessary to conduct a screening trial or study in Sweden. They advocated that screening programmes should be implemented because early detection of lung cancer can improve outcomes.*

Opportunity 3

Recommendation

- Decreasing the time between EMA approval and reimbursement of new treatments may help Sweden introduce innovations in care more effectively.

Rationale

- *Indicator 13: Workshop participants cited the gap between EMA approval and reimbursement in Sweden. Access to clinical studies and compassionate use can help to alleviate some of the pressure in the short term (only available in Sweden if the product is not available for another indication). Longer term it is important to ensure that medications are available—in a financially sustainable manner—as soon as possible after they have been approved. Failing to do so can create a two-tiered system whereby only those who can afford to pay for the medication obtain access.*

Opportunity 4

Recommendation

- Cancer registries lack clinical data. In Sweden, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: Sweden's cancer registry has been evaluated as being high quality on a national basis and the complete vital registration component has been evaluated as being medium quality. Clinicians may find that a detailed, clinical cancer registry could help to improve the overall care that lung cancer patients receive; it may also help ensure equity between regions.*

Methods

An initial literature review identified key frameworks and programmes that have been previously used to prioritise policy approaches for the prevention and control of lung cancer in a range of countries. From this a draft set of indicators was developed. An editorial advisory board was then convened to review and advise on the development of the indicator framework. Out of this process, The EIU identified a set of 17 indicators to evaluate each selected country across five domains.

A range of international and national sources were used for the data collection. The EIU team carried out both primary and secondary research to identify recent authoritative data to populate the country scorecard. Judgments were made based on the best information available. Because of the nature of scoring—wherein complex matters are collapsed into simple scores—we note that not all readers will agree with all scores. After draft scores were assigned, the EIU attended a workshop of external country-based experts, hosted by the sponsor, in order to discuss the scores and help develop recommendations.

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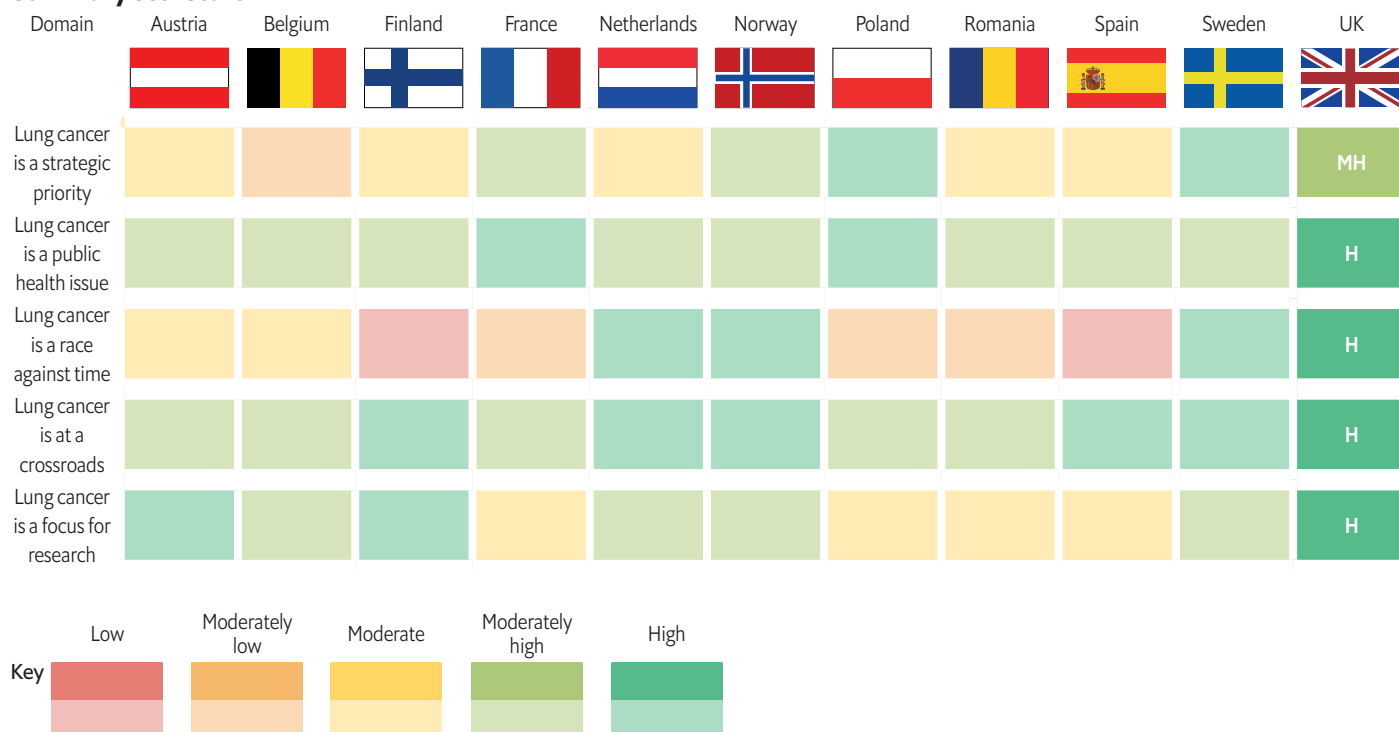
United Kingdom: Lung Cancer Country Profile



The United Kingdom performs strongly across all five of the domains, scoring 'high' throughout except for the first domain—which examines lung cancer as a strategic priority—where it scores 'moderately high'. The UK's strong showing is due to having comprehensive lung cancer clinical guidelines that incorporate fast tracking suspected lung cancer patients with time-frames for diagnostic referral, rapid referral to treatment, good use of histological testing and availability of treatment and referral pathways for supportive/palliative care. The reason for the slight dip in domain 1 is because the national cancer control plan does not identify a funding source, the lung cancer clinical guidelines do not discuss screening, and there is no specific lung cancer control plan. While scoring well overall, there are challenges in the UK, including the need for the guidelines to include the psychological burden of lung cancer and a pathway for psychological support services. We discuss opportunities for improvement at the end of this country profile.

The nations comprising the United Kingdom have taken a decentralised approach to addressing lung cancer in line with their devolved health systems. This has reinforced discrepancies between what is happening in each nation. While Northern Ireland once had the best 5-year survival rates for lung cancer in the UK, these rates have not kept pace with improvements seen elsewhere. Wales has published its own Cancer Delivery Plans and has one focused on lung cancer. Scotland has a Cancer Strategy that covers the patient's whole journey from early detection onward and it is currently being reviewed. Building upon the success of a pilot study in Manchester, published in March 2019, England has initiated an intervention targeting people at high risk for lung cancer in ten sites.

Summary scorecard



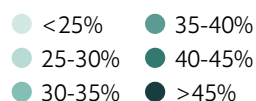
Sponsored by



United Kingdom

Lung cancer incidence

(Rate per 100,000, 2017)



United Kingdom

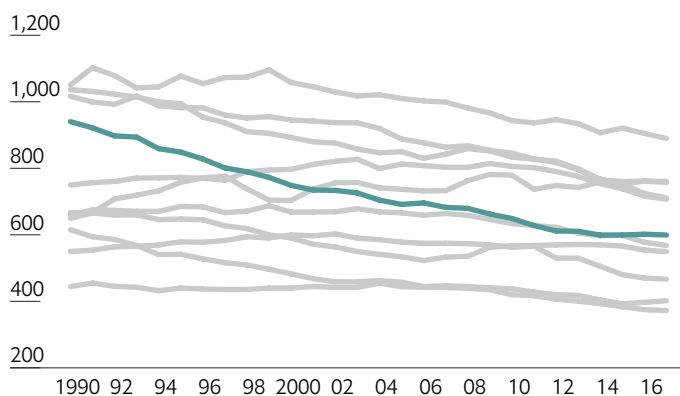
Lung cancer in numbers

Lung cancer statistics	United Kingdom	Europe	Global
Rate per 100,000, 2017			
Incidence	40	33	27
Prevalence	77	54	41
Mortality	30	27	24
Disability-Adjusted Life Years (DALYs)	599	628	503
Years Lived with Disability (YLDs)	10	8	7
Years of Life Lost (YLLs)	589	619	496

Source: Global Burden of Disease¹

Burden trend

(DALY rate per 100,000, 2017)



Source: Global Burden of Disease, 2017.¹

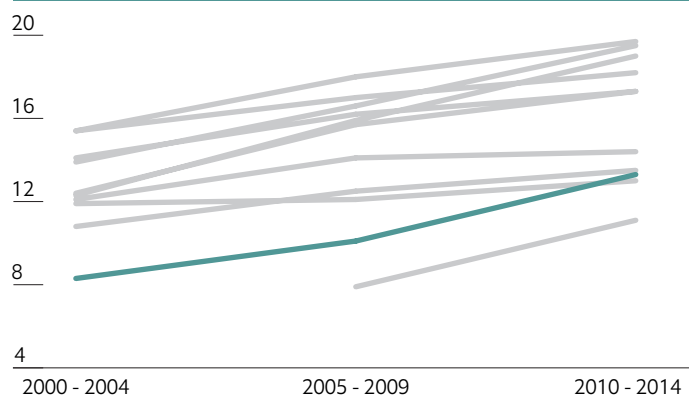
The costs of tobacco

Tobacco cost the economy £30,424 million in terms of direct costs to health expenditures and indirect costs due to lost productivity from morbidity and early mortality.²

Every year, tobacco-related diseases cause more than 114,500 deaths in the United Kingdom.²

Survival trend

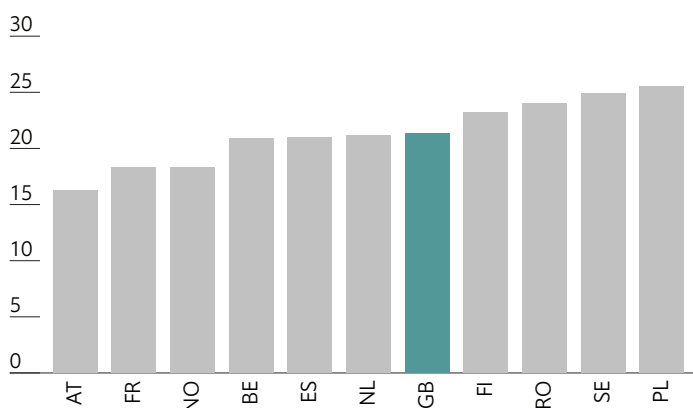
(% 5 year survival)



Source: CONCORD-3, 2018.³

Burden

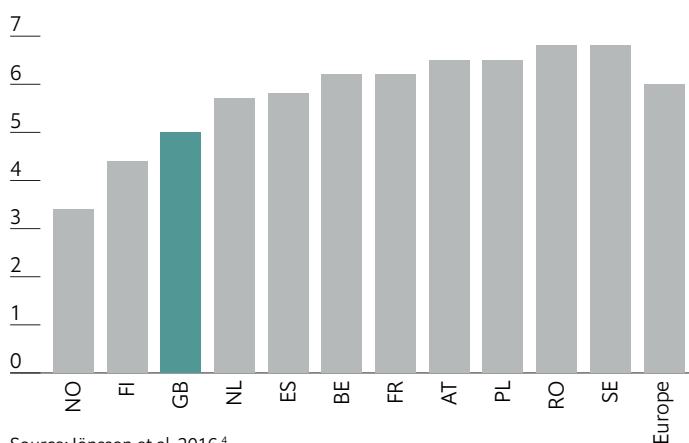
Lung cancer DALYs as a proportion of all cancer DALYs, 2017



Source: Global Burden of Disease, 2017.¹

Spend

Cost of cancer as a % of total healthcare spending, 2016



Source: Jönsson et al, 2016.⁴

Scorecard results

Indicator	Range	Score	Justification
Lung cancer is a strategic priority			
1 Operational, comprehensive, up to date national cancer control plan	0 – 5	3	<ul style="list-style-type: none"> ● An operational National Cancer Control Plan was published by the Department of Health in 2015.⁵ ● NHS England will sponsor an independently chaired National Cancer Advisory Board to oversee and advise on implementation of the national strategy. This body should prepare an annual report for the CEOs of the seven Arm's Length Bodies and the Secretary of State for Health. ● The national cancer control plan does not identify a funding source. ● A specific lung cancer control plan has neither been published nor discussed by the government or health ministry.
2 Comprehensive clinical guidelines for lung cancer	0 – 6	5	<ul style="list-style-type: none"> ● Lung cancer clinical guidelines published by the National Institute of Clinical Evidence in March 2019.⁶ ● Guidelines mention diagnosis and treatment. ● Guidelines discuss supportive / palliative care. Additional guidance on supportive / palliative care was published for all cancers in 2004. ● Guidelines include shared decision making as they mention discussing the benefits and risks with the patient and note the importance of giving patients time to make an informed choice. ● Guidelines do not mention screening.
Lung cancer is a public health issue			
3 Tobacco control policies and public health measures	0 – 9	9	<ul style="list-style-type: none"> ● National objectives on tobacco control and a national agency for tobacco control exist.⁷ ● UK is party to World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC). ● Advertising is banned on national TV and radio. ● Law mandates that health warnings appear on tobacco packages. ● At least one national mass media campaign ran during the survey period (up to 2016). ● National smoke-free legislation exists for indoor offices, restaurants/cafes/pubs/bars and public transportation.
4 E-cigarettes regulation and public health measures	0 – 4	2	<ul style="list-style-type: none"> ● Safety, quality standards and regulation are in place for e-cigarettes. ● The sale of e-cigarettes is prohibited to people under 18 years of age. ● Advertising is permitted in certain media directly to the general public, such as billboards, posters on public transportation and cinema adverts. ● E-cigarette use is not covered by smoke-free legislation. Public Health England (PHE) guidance (2015) specifically states that "it is not appropriate to prohibit e-cigarette use in health trusts and prisons as part of smoke-free policies unless there is a strong rationale to do so."
5 National policies and programmes for environmental exposure control	0 – 2	2	<ul style="list-style-type: none"> ● National Air Quality Strategy published in 2017. ● WHO states that the UK has a radon control programme and PHE guidance for newly built homes was published in 2018.
6 Evidence-based approach to lung cancer screening	0 – 1	1	<ul style="list-style-type: none"> ● Building upon the success of a pilot study in Manchester, published in March 2019, England has initiated an intervention targeting people at high risk for lung cancer in ten sites. People (55-74 years of age) who are at increased risk of lung cancer will be invited for a lung health check with chest scan, if appropriate. Scans will take place in a mobile unit or hospital setting. The goal is to identify lung cancer earlier as well as other health conditions, i.e. COPD. The pilot study quadrupled early detection of lung cancer.
7 Patient organisations involvement in policy development	0 – 3	3	<ul style="list-style-type: none"> ● Lung cancer clinical guidelines developed with direct participation of a patient representative and carer. ● Civil society has the opportunity to comment on recommendations.

Indicator	Range	Score	Justification
Lung cancer is a race against time			
8 Suspected lung cancer patient diagnosis within a specific time frame	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer clinical guidelines state that suspected lung cancer patients should be offered an urgent chest x-ray (performed within 2 weeks) if they are aged 40 or over if they have two or more of the following unexplained symptoms or if they have ever smoked and have one or more of the following unexplained symptoms: cough, fatigue, shortness of breath, chest pain, weight loss, or loss of appetite. An urgent chest x-ray (within 2 weeks) in people aged 40 or over with any of the following: persistent or recurrent chest infection, finger clubbing, supraclavicular lymphadenopathy or persistent cervical lymphadenopathy, chest signs consistent with lung cancer thrombocytosis.
9 Guidelines/ pathways for rapid referral to quality care	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines state that referral to secondary / tertiary care for treatment is to be provided “without undue delay for people who have lung cancer that is suitable for radical treatment or chemotherapy, or who need radiotherapy or ablative treatment for relief of symptoms.” Furthermore, the guidelines state that arrangements are made “for people with small-cell lung cancer (SCLC) to have an assessment by a thoracic oncologist within 1 week of deciding to recommend treatment.” ● Lung cancer clinical guidelines state that everyone with a suspected diagnosis of lung cancer is to be referred to a member of a lung cancer multidisciplinary team (usually a chest physician).
Lung cancer is at a crossroads			
10 Medical and surgical specialists	unscored	number per 100,000	<ul style="list-style-type: none"> ● In 2016: 4.12 pulmonologists 1.53 thoracic surgeons 13.37 general surgeons 3.8 oncologists.⁸
11 Radiotherapy accessibility	unscored	unmet need	<ul style="list-style-type: none"> ● -281 is the difference between demand and supply of radiotherapy megavoltage machines. (minus sign = deficit)⁹ ● There is an insufficient supply of radiotherapy megavoltage machines in relation to demand. ● Percent of unmet need between observed and expected number of radiotherapy megavoltage machines is -46.9%. ● Access to stereotactic radiotherapy (SABR) is limited in many areas. ● No data available to assess the length of time a lung cancer patient must wait in order to access radiotherapy treatment.
12 Tumour testing recommendations and accessibility	0 – 6	6	<ul style="list-style-type: none"> ● Lung cancer guidelines mention histological and molecular testing. ● Lung cancer guidelines mention EGFR, ALK, ROS 1 and PD-L1. ● EGFR, ALK, ROS1 and PD-L1 approved and reimbursed.
13 Key personalised medicines reimbursement and accessibility	0 – 10	10	<ul style="list-style-type: none"> ● All five of the tyrosine kinase inhibitors and anti PD1 antibodies we studied are registered and available for the majority of patients through the health system.
14 Understanding psychological burden of lung cancer and access to support services	0 – 2	0	<ul style="list-style-type: none"> ● Lung cancer guidelines do not specifically include psychological assessment or mention the psychological burden of lung cancer. ● However, the guidelines state that “other symptoms, including weight loss, loss of appetite, depression and difficulty swallowing, should be managed by multidisciplinary groups that include supportive and palliative care professionals.” ● No referral pathway for psychological support services in lung cancer guidelines.
15 Patient access to supportive / palliative care services	0 – 2	2	<ul style="list-style-type: none"> ● Lung cancer guidelines discuss supportive and palliative care and state that care should be provided by general and specialist palliative care providers in line with the NICE guidance on improving supportive and palliative care for adults with cancer. ● Specific supportive and palliative care guidelines exist for all cancers. ● Medical oncology specialty training includes competencies on supportive therapies and palliative care which include management of pain, antiemetic agents, growth factors, blood product support, nutritional support and rehabilitation.
Lung cancer is a focus for research			
16 Clinical and outcomes data collection	0 – 7	7	<ul style="list-style-type: none"> ● High quality population based cancer registry (national) (3 points out of a possible 3)¹⁰ ● High quality complete vital registration (4 points out of a possible 4)
17 Research support and funding	unscored	R&D as % of GDP; ratio of clinical trials	<ul style="list-style-type: none"> ● 1.69% of GDP spent on research and development in 2016.¹¹ ● Number of clinical trials between 2009-2018 = 502¹² ● The ratio of 2009-2018 clinical trials to GDP (billions) = 0.19

Opportunities for Improvement

Opportunity 1

Recommendation

- Screening and other forms of early detection can improve outcomes by identifying lung cancer at an early stage. The pilot study on lung cancer screening in Manchester was expanded to ten sites in England in March 2019. Northern Ireland, Scotland and Wales may benefit from conducting similar studies.

Rationale

- *Indicator 6: An evidence based approach to lung cancer screening / early detection can improve treatment outcomes by identifying lung cancer early. Workshop participants noted that early detection and timely diagnosis is the biggest challenge in each of the devolved nations of the UK. The screening pilot study in North Manchester was shown to quadruple the early detection of lung cancer and has now been expanded to ten sites in England. Northern Ireland, Scotland and Wales might benefit from participating in a similar study. Wales is currently exploring the approach they should take. However, there is concern that healthcare systems may not be able to adequately cope with an increased demand from the increase in the number of patients diagnosed through a screening programme.*

Opportunity 2

Recommendation

- Data collected via the National Lung Cancer Audit has led to improvements in the quality of care delivered to lung cancer patients. Expanding it to cover the entire UK could help to improve the current understanding of how the needs in each nation may differ.

Rationale

- *Indicator 16: The National Lung Cancer Audit was developed to respond to findings in the late 1990s that outcomes for lung cancer patients in the UK lagged behind outcomes seen in other western countries and also varied within the UK. The National Lung Cancer Audit covers England, Wales, Guernsey and Jersey. Following a change in legislation and adaptation of IT systems, Northern Ireland is hoping to be included in the near future.*

Opportunity 3

Recommendation

- Ensure that the psychological burden faced by lung cancer patients is addressed with pathways to access psychological support services.

Rationale

- *Indicator 14: The UK neither includes psychological assessment, mentions the psychological burden of lung cancer nor provides a referral pathway for psychological support services in their lung cancer guidelines. Providing a pathway in the guidelines provides clear and practical steps to ensure that patients can receive the support that they need. Each of the devolved nations of the UK note that this area needs to be improved. In Northern Ireland, some nurses only provide psychological support at the time of diagnosis. In Wales, as in England, a specialist nurse provides an overarching holistic approach but not every patient receives this.*

Opportunity 4

Recommendation

- Cancer registries lack clinical data. In the UK, a clinical cancer registry could provide helpful data.

Rationale

- *Indicator 16: The UK's cancer registry and vital registration data collection systems have been evaluated as being of high quality. Clinicians have suggested that a stronger clinical component to the cancer registry could help to improve the overall care that lung cancer patients receive. However, it was noted that in practical terms the National Lung Cancer Audit has fulfilled this need for clinicians (at least in the nations that use it—see opportunity 2, above).*

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