



Ending substandard treatment in lung cancer

Lung cancer kills more people in Europe than any other type of cancer, yet efforts to monitor and improve standards of treatment and care have lagged behind those of less fatal cancers, such as breast and prostate. **Marc Beishon** talked to some of the specialists who are determined to turn this around.

“**A** fatalistic professional approach.” This is how Erik Jakobsen, a leading Danish thoracic surgeon and head of the Danish Lung Cancer Registry, describes the attitude that used to dominate thinking about treating lung cancer, and which invariably led to the conclusion that reductions in mortality would only come from better prevention and detection (*J Thorac Surg* 2013, 8:1238–47).

Understandable, possibly, given that the five-year survival rate in the latest EURO CARE study (EURO CARE-5) averaged 13% across Europe, showing only marginal improvement over previous EURO CARE cohorts.

Yet focusing on prevention and detection is of no use to the more than 400,000 people diagnosed with the

disease in Europe every year. What is more, it overlooks the major disparities in outcomes that have been recorded not only between European countries but also within them. These point to considerable potential for improving outcomes by ensuring that all centres that treat lung cancer deliver treatment and care to an equally high standard.

Comparative data on cancer outcomes by hospital or health region are quite hard to come by. Those that do exist indicate some quite shocking disparities, at least in the case of lung cancer. In England, for example, one of the few countries where widespread data are available, the proportion of lung cancer patients alive after one year in 2013 varied from 55% down to just 12% among the hospitals that treat the disease, and even when outliers at

the top and bottom are removed, the variation ranges from 48% to 20%.

Those figures are cited by Mick Peake, who has led several initiatives in lung cancer in the UK, including the National Lung Cancer Audit Programme, and he has also been the lead for lung cancer quality improvement.

Peake is neither an oncologist nor a lung cancer surgeon, he is a respiratory physician – a specialism that, along with epidemiology, has been taking a lead in work on quality and variation of lung cancer care in Europe. The European Initiative for Quality Management in Lung Cancer Care, for example – a task force of the European Respiratory Society – is led by German respiratory physician Torsten Blum.

Much of this work is recent and

researchers are only just starting to identify underlying reasons for such alarming inconsistency, and to put forward comparative information on the ways that lung cancer is treated.

Denmark and the UK are two countries that have been particularly active in this field, not least because of their comparatively poor showing within the EURO CARE league tables. Denmark was one of the first countries to set up a lung cancer group, back in 1991. The work it did, establishing national clinical guidelines, a lung cancer registry, and a range of quality indicators, offers valuable evidence not just about the disparities in outcomes between treatment centres, but the potential for reducing those disparities and improving overall outcomes.

Findings reported by Jakobsen and colleagues in the 2013 *Journal of Thoracic Surgery* paper show that one-year survival rates increased between 2003 and 2011 from 36.6% to 42.7%, the five-year rates increased from 9.8% to 12.1% and the five-year survival rates for patients whose lung cancers were surgically resected increased by almost nine percentage points, from 39.5% to 48.1%.

The key point, says Jakobsen, is that improvements can be made independently of efforts to tackle smoking and improve early diagnosis. With colleagues including Peake in the UK, and the epidemiology team at King's College London, he has taken part in a number of studies on England, as well as Denmark, noting that one of the reasons the two countries collaborate is that they both have high quality data and are part of an international cancer benchmarking partnership set up by the UK. Few other countries, including major ones such as France and Germany, have such data, he says.

Higher volumes give better outcomes

As Jakobsen says, one of the most obvious factors that has emerged from the data is that high volume lung cancer units have better outcomes, and they do so even when they have a patient mix with more co-morbidities and of lower socio-economic status. This has been reported

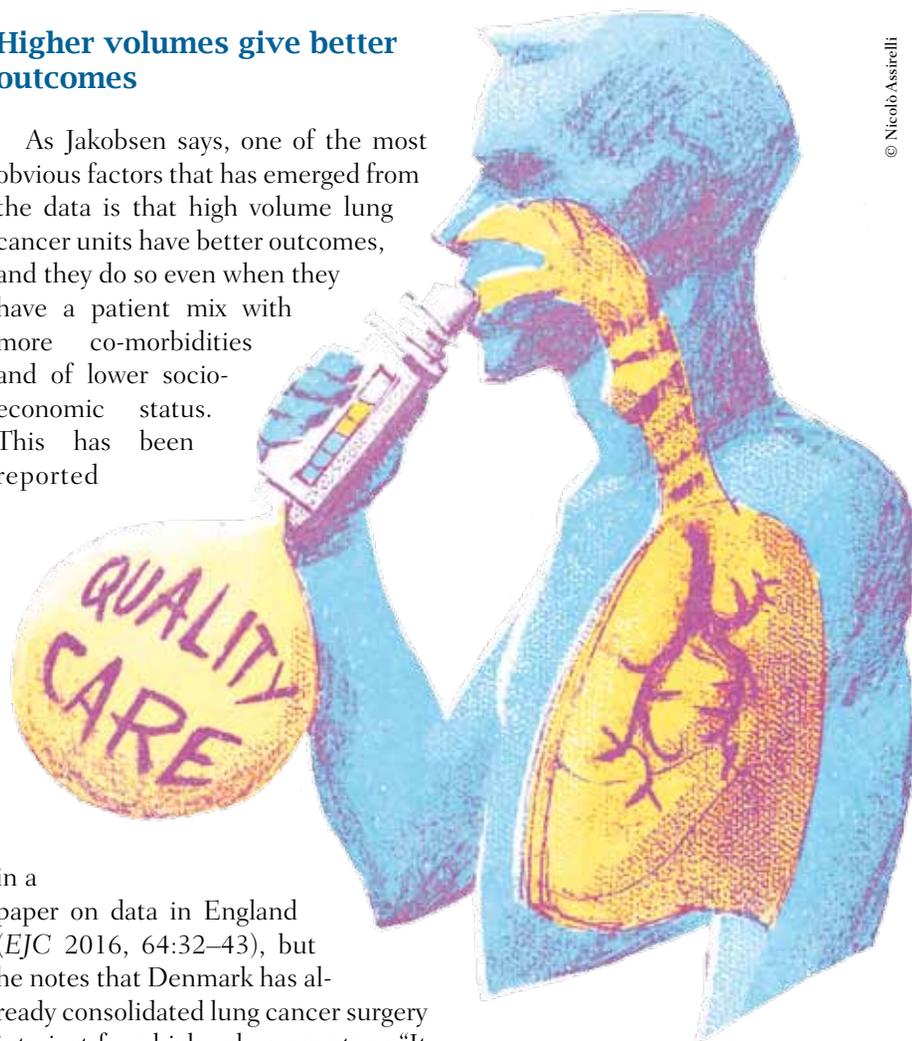
in a paper on data in England (*EJC* 2016, 64:32–43), but he notes that Denmark has already consolidated lung cancer surgery into just four high volume centres: “It is clear to me as a surgeon that if you have a low volume hospital – and England still has many – the chances of lower competence among the MDT [multidisciplinary team] are higher.

“For example, we have shown from the Danish registry that the quality of pre-treatment evaluation procedures is very important in outcomes; you need to ascertain the correct stage of cancer before treatment, and a problem with low volume centres is they may not have access to PET-CT and high quality staging procedures, or within a reasonable time. When you have the participation of expert radiologists, pathologists and lung physicians you get a better chance of high quality

treatment.”

As Jakobsen adds, it is not enough just to have an MDT meeting – it has to be provided with high quality information to make correct decisions. While Denmark has just four surgical centres, it has also been consolidating evaluation units, down from some 50 in the year 2000 to about 12.

High volume centres are also more likely to have thoracic surgeons trained in advanced procedures, including video assisted operations and organ sparing. In England, notes Jakobsen, low volume centres perform more total lung removals (pneumonectomy) as a proportion, which are associated with a higher postoperative death rate and greater



Quality indicators



Indicators suggested by various groups for the purpose of audit and benchmarking of the quality of lung cancer care include:

- Survival rates at 1,2 & 5 years
- Survival rates after surgery at 30 days and 1, 2 & 5 years
- Consideration by a multidisciplinary team
- PET-CT scan before surgery or radical radiotherapy
- Histological stage confirmation
- Seen by clinical nurse specialist
- Performance and function status assessed
- Resection rate for patients with non-small-cell lung cancer (NSCLC)
- Radical treatment rates for patients with stage I/II NSCLC
- Systematic anticancer treatment rates for patients with stage IIIB/IV NSCLC and performance status 0-1
- Active anticancer treatment rates for patients
- Chemotherapy rates for patients with small-cell lung cancer
- Waiting times from referral to receiving first anticancer treatment
- Completeness of data collection

morbidity. England's pneumonectomy rate is double that of Denmark, he says, although it has been going down.

Also associated with better outcomes is the number of patients who actually have a surgical operation – the resection rate – which again is rising in England, though for non-small-cell lung cancer (NSCLC) it remains lower than in the benchmark countries (which also include Australia, Canada, Norway and Sweden). However, Jakobsen cautions that the resection rate must be seen in the context of the overall treatment rate with curative intent, as stereotactic radiotherapy (itself not available in many locations) is a good alternative to surgery in patients with high comorbidity and low lung function. There is a similar story with chemoradiation treatment, which is often led by oncologists (and high volume centres are generally more likely to have access to the latest drugs).

“But very few countries have this data,” says Jakobsen. “We are aiming to collect this in the Danish registry. Often, you have data on the treatment that was

planned, but not what was actually given – about half of patients don't get their planned treatment, and this can have a big impact on survival.”

About 35% of patients in Denmark are currently eligible for curative treatment, he says, “and our target is 40% for NSCLC. But because of the lack of country data we don't know how this compares with others.”

As for outcomes, Jakobsen stresses that it is not just the one- to five-year survival figures that matter, but also mortality at 30 and 90 days, and high volume centres have an advantage here as well, as they are more likely to have a highly skilled, multidisciplinary post-operative team in place.

Multidisciplinary: what it means in lung cancer

Peake takes up the theme of multidisciplinary, saying that in England there are currently more than 150 lung cancer teams, and they

cannot possibly all have fully expert professionals, and that volumes vary from smaller hospitals seeing about 50 cases up to 600 at the largest centre. Despite the UK's pioneering implementation of cancer care pathways, surgical centres have not always had specialist thoracic surgeons based at them, and surgeons have not always been available to attend MDTs. Peake says that, earlier in his career, he'd seen many patients in outlying hospitals who, in retrospect, could have been operated on had a specialist surgeon been directly involved.

Since the UK has started feeding back data from its lung cancer audit, and since nearly all patients are now discussed in a MDT, operations have more than doubled from about 3,250 in 2005 to 7,250 in 2014, he says.

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While resection rates are still lower than other countries, as reported in the literature, like Jakobsen he expresses doubt about the quality of data from elsewhere, and also echoes the point that this is not just about surgery, as lung cancer treatment has become more specialised, with new molecular targets and stereotactic radiotherapy.

In the MDT, he also highlights the role of nurse specialists – “They often act as advocates for patients and press for a specialist opinion on a patient's fitness for treatment.” There is even a study showing an association between being reviewed by a cancer nurse

specialist and a higher likelihood of receiving active treatment (*Thorax* 2011; 6:Suppl 4 A42-43).

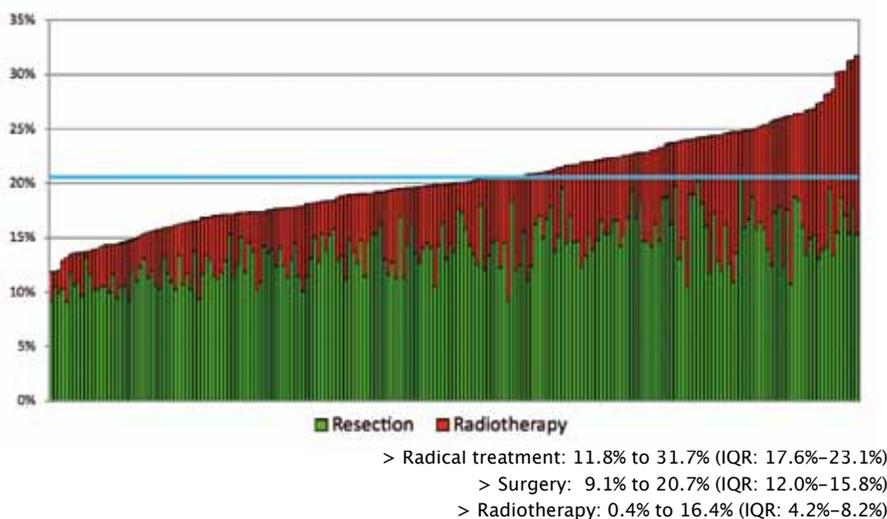
Peake has a huge amount of other data and studies at his fingertips concerning lung cancer in England, from how primary care doctors with lower threshold rates for referral can improve outcomes, to the impact that distance from hospitals, age and socioeconomic status have on treatment uptake, to trends in take up of various therapies, and indeed the role of respiratory physicians, who are also known as pulmonologists/pneumologists, or thoracic/chest physicians.

These specialists play a pivotal role say Peake and colleagues (*Respirology* 2015, 20:884-8). While countries do vary in service structure, they write, “Most patients with suspected lung cancer are initially referred to a respiratory physician for confirmation or exclusion of this diagnosis, as well as staging of confirmed lung cancer, and assessment of fitness for any potential therapy.” In many instances, they add, “it is the respiratory physician who is the chair of the MDT and provides leadership and strategic direction for the team.”

It is acknowledged by Peake and colleagues, though, that there is little actual ‘trial level’ evidence for the effectiveness of lung cancer MDTs, and even less for the role of respiratory physicians, and “conclusions are based both on common sense and clinical experience.” It all points to a need to develop the evidence, although controlled trials are not likely to ever happen – which is an issue common to other cancers.

Torsten Blum, who leads the European Initiative for Quality Management in Lung Cancer Care, also stresses the role of respiratory experts. A review he co-authored, “The lung cancer patient, the pneumologist

Treatment varies widely from place to place



Quality matters. This graph, published by Public Health England, shows that people are almost three times as likely to receive radical treatment for non-small-cell lung cancer in local health services with the highest rates of radical treatment compared with the lowest. The picture is likely to be replicated in many other countries, but most do not collect or publish the data.

Source: Daniela Tataru et al. (2016) Geographical Variation in the Use of Radiotherapy and Surgical Resection for Treatment of Non-Small Cell Lung Cancer in England. National Cancer Registration & Analysis Service, Public Health England

and palliative care: a developing alliance’, finds that the value of early palliative care is not being realised, and looks at how pneumologists can raise their game (*Eur Respir J* 2015, 45:211–26). He makes the point that, in Germany, respiratory physicians can also administer systemic therapy.

Improving quality across Europe

The European Initiative for Quality Management in Lung Cancer Care is probably the first attempt to capture data on the quality of care across Europe. A first paper was published in 2014, detailing an extensive literature review, a baseline survey of healthcare infrastructure, benchmarking of guidelines, and the feasibility of collecting

clinical data from European countries (*Eur Respir J* 2014, 43:1254–77).

As Blum says, it has confirmed the picture of widespread inequalities among countries, especially in access to radiotherapy and new targeted drugs (and now immunotherapies are also becoming important in lung cancer). “We also see differences in qualifications and specialisms of personnel. For example, we believe surgeons should specialise in thoracic surgery, but some countries don’t have a board exam for it, only for general or perhaps cardiothoracic surgery,” says Blum.

Waiting times for scans and treatment in the UK, which has a primary care/outpatient system, contribute to higher mortality there he feels, although Jakobsen says that waiting a bit longer for treatment is not crucial (but late diagnosis is).

In general, the paper also found that there was no other project of the same scope – most other studies were institutional or regional, and addressed single facets of the lung cancer pathway. The (open access) paper includes tables showing what type of professional delivers certain modalities, including palliative care, what infrastructure delivers care in each country, and how countries and hospitals vary in histological confirmation and surgical resection rates.

There is also detail on who makes up MDTs in the hospitals surveyed from European countries, and Blum says the task force has since carried out interviews in 25 countries to dig deeper into MDT features. “We have not published yet, but one finding is that MDTs tend to channel patients into various treatment pathways – such as surgical, palliative or systemic treatment – but then these pathways become unidisciplinary with no teamwork. There should be multidisciplinary working along the entire pathway, but this seems to be hard to do owing to lack of resources.” What can be termed extended MDTs – with professionals such as psychologists and social workers – are also not in place in most countries.

The task force is aiming to publish standards for lung cancer registries and centres in Europe. “We want to define our gold standard of care – the idea is not to run a certification system but to help countries make a self-assessment to improve their care quality.”

Germany, he notes, is one of the leaders in certification, including it for lung cancer in 2009. Blum’s centre – Lungenklinik Heckeshorn, in Berlin – was a pilot. “Having an external auditor is helpful – we found discussion on structuring MDT meetings particularly useful. Our main criticism is that it is too focused on infrastructure and outcomes, and is lacking in process quality.” As

an example, he gives the delivery of systemic chemotherapy – “Do you assess every cycle to adjust dosages? How are complications managed? Standards are needed for certain processes to guarantee quality.”

“Unacceptable variation remains in standards of care between organisations”

In the UK, Peake notes that a national peer-review system for cancer units is still in place, although not as in-depth as it was a few years ago when lung MDTs used to receive regular visits from peers – now it is mostly done based on data. The UK National Lung Cancer Audit for 2016 was published with commendable speed, covering patients diagnosed in 2015. It shows encouraging improvements, such as one-year survival at 38% compared with 31% in 2010, histological confirmation rates have risen, and the proportion of patients treated surgically (excluding those with small-cell lung cancer) rose to 16.8%. But “there remains wide and unacceptable variation in standards of care between organisations,” the audit report notes.

Putting survival on policy agendas

Patient groups are now becoming much more vocal about the lottery that exists for care in countries. For example, the UK Lung Cancer Coalition (UKLCC) is calling for governments, commissioners and the healthcare community to work together to raise

five-year lung cancer survival rates to 25% by 2025 across the UK, and has recently published a report, ‘25 by 25: a Ten-year Strategy to Improve Lung Cancer Survival Rates’, in which it makes 20 recommendations, including the introduction of screening for groups at risk (informed by a Dutch–Belgian randomised trial on using CT scans, known as NELSON).

At the European level, LuCE (www.lungcancereurope.eu) is a relatively recent arrival to the advocacy movement. Modelled on Europa Donna, the breast cancer umbrella organisation of national members, its launch was supported by the European School of Oncology. It has followed up a position paper from 2015 with a report launched last November at the European Parliament. The ‘LuCE report on lung cancer’ presents the incidence, survival and mortality figures, and one of the key messages is to address inequalities that emerge from this data, especially in eastern Europe, and engage member groups in addressing concerns in their countries.

It stresses access to new treatments but recognises that they must be provided on the basis of evidence, such as by using ESMO’s Magnitude of Clinical Benefit Scale. As the LuCE board members say: “Spending on lung cancer doesn’t automatically translate into improved outcomes, but more effective management of available resources to provide patient-centric care, does.”

The conclusion about patients with lung cancer, like those with other major cancer types, is that they need care in high quality, high volume multidisciplinary centres that help to iron out inequalities. There is much to do in prevention and early diagnosis, not least to reduce the numbers first seen in emergency departments (which vary from about 23% to 47% across Europe). But at the same time a standard of care quality for treatment centres, as



LuCE Lung Cancer Europe

Lung Cancer Europe (LuCE), the pan-European advocacy group, is calling for action to improve screening and early diagnosis, access to quality treatment, research and support for people with lung cancer. This image is part of their campaign to challenge stereotypes and stigma surrounding lung cancer, which isolates patients and can act as a barrier to seeking timely help, diagnosis and treatment.

suggested by the European Respiratory Society task force, must have wider discussion and ultimately promotion – and the emphasis should be more on patient needs rather than just raw outcome measures.

Other work in this direction includes 'Defining a standard set of patient-centred outcomes for lung cancer', a paper by the lung cancer working group of the International Consortium for Health Outcomes Measurement (ICHOM), again with

Peake as one of the key movers. As the authors say, lung cancer outcome measurement has been mostly limited to survival, and there is a need to include measures of the value of treatments according to other factors such as complications, degree of health, and quality at end of life (see *Eur Respir J* 2016, 48:852–60).

And when it comes to lung cancer, addressing public attitudes and prejudices are an essential part of improving outcomes. This is not just

about fatalism, and raising awareness of the disparities in the quality of treatment and the importance of seeking out the best centres. It is also, as LuCE emphasises, about challenging widely held, and ill-informed, negative attitudes that people with lung cancer 'have brought the disease on themselves' through smoking, which as LuCE says, "creates a stigma which can isolate patients, and creates barriers to seeking timely help, diagnosis and treatment, which could ultimately save lives."