UNITED KINGDOM
LUNG CANCER COALITION

Lung Cancer Plan: improving lung cancer survival in the UK

UK Lung Cancer Coalition
November 2007

Introduction from Gill Oliver, UK Lung Cancer Coalition Chair

Huge strides have been made in cancer prevention and treatment. Thankfully, for many people, a diagnosis of cancer no longer comes with an automatic death sentence and they can look forward to years of life and health.

But the need to move forward in lung cancer prevention, early diagnosis, treatment and care is urgent and compelling. Lung cancer still has extremely poor survival rates and is the biggest cause of death from cancer in the UK. Each year more than 38,000 new cases are diagnosed and the disease claims over 33,500 lives[1] – more than the death toll from breast cancer, bowel cancer and leukaemia combined.

Lung cancer remains a Cinderella cancer – unfairly tainted with the stigma of being perceived as 'a smoker's disease', despite the many thousands of non-smokers who develop it. Many patients with lung cancer experience a sense of 'shame and blame'. Those that have smoked may feel a sense of guilt about their health and that in some way they have 'brought illness on themselves'. Tackling this social stigma is important, since it can lead to delayed presentation of symptoms to GPs, late diagnosis and ineffective treatment.

Whatever the cause of their disease, all lung cancer patients deserve the best in support and services. Sadly, not many lung cancer patients are well enough to speak about their disease and demand improvements in cancer services. It's one of the reasons why the UK Lung Cancer Coalition (UKLCC) came together: to campaign on behalf of lung cancer patients and their families. The UKLCC's members - including doctors, nurses, researchers, charities and healthcare companies - are united in their belief that more can and must be done to prioritise lung cancer and improve survival.

Thanks to concerted campaigning over many years, our public places and workplaces are now smoke-free. Already the benefits are being felt by all and, in time, reductions in smoking prevalence will lead to a fall in smoking-related diseases. But this won't completely tick the box for lung cancer.

A recent analysis showed that our survival rates lag well below the European average, despite our relatively high national expenditure on health services. Only Malta (with a five-year survival rate of 4.6%) has a lower survival rate than Scotland (8.2%) and England (8.4%). All UK countries have a long way to go before reaching the standard set in Iceland, where 16.8% of lung cancer patients are still alive five years after diagnosis[2]. The National Cancer Director, Mike Richards, believes that "the poor results from the UK were attributable mainly to patients having more advanced disease at diagnosis," which "indicates that particular emphasis should be put on achieving earlier diagnosis".[3]

Clearly we still have much to learn and do. The Cancer Reform Strategy expected this winter will build on the progress of the NHS Cancer Plan, and identify where we still need to reform services. UKLCC members have been active in the groups drawing the Cancer Reform Strategy together. To contribute to the implementation of this and to generate fresh ideas for how to go further for lung cancer specifically, the UKLCC gathered together a group of lung cancer experts from across the country to pool their thoughts on a way forward.

Their view from the front-line has shaped our strategy. This report sets out our analysis of the current situation and the pressing areas where action needs to happen. It's not exhaustive – there's much more that could be done – but we believe this 12-point plan highlights the areas where the biggest gains could be made. Bringing standards of care across the NHS up to that already happening in the best centres would, we believe, save many thousands of lives.

It's a huge challenge, and it will take collaboration with the NHS and Government, patients and carers, industry and voluntary sector. But we believe that the lives of lung cancer patients are worth fighting for. Working together, we believe we can double lung cancer survival rates – and that would be something of which we could all be proud.

Dame Gill Oliver
Chair, UK Lung Cancer Coalition
November 2007

[1] Figures from Cancer Research UK, available at: http://info.cancerresearchuk.org/cancerstats/types/lung/
[2] Verdecchia A, Francisci S, Brenner H, Gatta G, Micheli A, Mangone L, Kunkler I, and the EUROCARE-4 working group. Recent cancer survival in Europe: a 2002-02 period analysis of EUROCARE-4 data. Lancet Oncology. Published online August 21, 2007
[3] Mike Richards. EUROCARE-4 studies bring new data on cancer survival. Lancet Oncology. Published online August 21, 2007

Our vision

The UK Lung Cancer Coalition is a coalition of the leading charities, clinicians, health professionals and healthcare companies with a commitment to lung cancer issues.

The UKLCC believes that more can be done to reduce the terrible death toll caused by lung cancer. Our vision is to succeed in meeting an ambitious "survival challenge":

"To double one year lung cancer survival by 2010 and five year survival by 2015*"

To do this, we are working toward the following objectives:

- Raise the general public's awareness of lung cancer – and especially encourage earlier presentation and symptom recognition
- Empower patients to take an active part in their care
- Understand and improve the patient's experience of being treated for and living with lung cancer
- Raise political awareness of lung cancer
- Raise the awareness of lung cancer amongst non-specialist healthcare professionals
- Improve lung cancer services in the UK
- Increase research funding for lung cancer
- Raise awareness of recent achievements in tackling lung cancer

By achieving the above objectives and by universally adopting the innovative and aggressive standards of lung cancer management already seen in the best centres in the NHS, we believe that the lung cancer "survival challenge" can be met and exceeded.

* based on survival rate figures from 1996-99

Our twelve point plan – the calls to action that will make a difference for lung cancer

The following twelve actions are those that the UKLCC believes are the priority areas and actions for tackling lung cancer.

We make the following calls for action:

Priority	Our call for action
1. Prevention	The UKLCC calls on the UK governments to commit to funding and implementing comprehensive national tobacco strategies.
2. Screening	We urge the UK Governments to implement a lung cancer screening pilot programme now.
3. Awareness	The UKLCC calls on the UK governments and health authorities to support primary care organisations in putting local strategies and initiatives in place to improve symptom awareness.
4. Primary care	We call on the health departments in all UK administrations to support research into risk stratification and patterns of presentation, and to encourage primary care organisations and healthcare professionals to engage with these.
5. Information and support	We call on the UK governments to ensure lung cancer patients feel informed about their disease and the support available, and empowered to make decisions about their treatment options in partnership with health professionals.
6. Diagnosis and staging	We call for the health departments in all UK administrations and the commissioners of cancer services to demand that all patients where lung cancer is suspected are referred directly to a highly specialised rapid access clinic which is part of a multidisciplinary team (MDT) which has timely access to the appropriate diagnostic and staging tools.
7. Treatment	The UKLCC calls for more lung cancer patients to be considered for active treatment, with all centres learning from those where innovative and aggressive cancer management is bringing about better patient outcomes.
8. End of life care	The UKLCC calls on primary care organisations to examine the provision they make for palliative care, and ensure that all lung cancer patients have access to the information and support services they need.
9. Managing care	Every MDT should be able to demonstrate that it is meeting national standards, with specialised representatives of each of the necessary disciplines present at every meeting. High quality data collection should be a necessary part of their activity.
10. Workforce capacity	The UKLCC calls on the health departments in all UK administrations to undertake a capacity review and deliver a workforce strategy to meet it, taking account of projected increases in demand and addressing current shortages in all key disciplines including specialist surgery and specialist nursing.
11. Research	The UKLCC calls on the UK governments to fund more research into the early detection and diagnosis of lung cancer and on the lung cancer research community to raise the bar - generating further high quality research into the prevention, detection and treatment of the disease and expanding access to clinical trials.
12. Data collection	All primary care organisations should participate in data collection for national audits – and should be held to account if they fail to submit their data.

In turn the UKLCC partners commit to working with the UK governments, health departments, NHS professionals, and others in order to achieve these calls.

Prevention

More than eight in ten lung cancers are caused by smoking[4]. The UKLCC welcomes the efforts already made to reduce the numbers of people smoking, especially the introduction of legislation to make public places smoke-free. This was campaigned for by many of our members, and is welcomed across the cancer community.

At least 5,000 cases a year are diagnosed in non-smokers – more than the number of cases of brain cancer, oral cancer, or bone cancer. The number of cases of lung cancer being diagnosed in non-smokers is increasing. UKLCC partners are researching this important area, but further research is needed into why these lung cancers occur.

However, given that most cases of lung cancer are caused by smoking, continuing efforts to reduce smoking prevalence through a range of tobacco control measures will be critical to reducing the future burden of lung cancer.

Cigarettes need to be less affordable, appealing and available, and cessation products need to be more appealing and available. Measures needed within a national strategy include investment in smoking cessation services, higher cigarette prices, further support for stop smoking services and the full independent regulation of the advertising, marketing and promotion of all tobacco and nicotine containing products, including the introduction of plain packaging and picture warnings.

Steps also need to be taken to tackle tobacco smuggling. Around one in six cigarettes and about half of hand-rolling tobacco smoked in Britain is illicit. This reduces the price, increases demand and accessibility to young people, and undermines national policies aimed at reducing smoking prevalence.

UKLCC CALL FOR ACTION: We call on the governments of the UK to commit to funding and implementing comprehensive national tobacco strategies.

[4]ASH Essential Information 02: Smoking Statistics: Illness and Death. Available at: http://newash.org.uk/files/documents/ASH_107.pdf

Patient Story – Leslie Ableson

Leslie Ableson is a very special cancer survivor. Diagnosed with lung cancer in 1993, he is one of Britain's longest survivors. Leslie says:

My story is one of hope – it is possible to beat lung cancer. As soon as I thought I had something wrong I went to my doctor, so my cancer was caught very early. I also had the best in treatment and care from my doctors and nurses. 14 years on, I see the same lung cancer doctor once a year for a check-up. I think he finds it as amazing as I do that I'm still going!

I know I'm one of the lucky ones. I'd like to see patients being pro-active and presenting their symptoms to their GP early. I'd like all lung cancer patients surviving for longer – and many more celebrating their 14-year survival anniversary!

Screening

Many lung cancer patients are diagnosed at a late stage so the promise of a reliable lung cancer screening test is appealing. At present there is no reliable screening test that has been proven to reduce overall lung cancer mortality at a population level and this is a high priority for the lung cancer research community. More research is needed, including investigating a variety of screening methods, potential biomarkers and the benefits of screening among different high-risk groups.

Research is underway in Europe and the USA into low-dose spiral CT scanning - a technique that allows detailed pictures to be taken of the lung and can spot potentially cancerous lesions smaller than 5mm in diameter. At present there is a lack of information on the economics of introducing and running a lung cancer screening programme in the NHS and in this field we are significantly behind many other developed countries. We are aware that a broad agreement has now been reached by funders on the need for such a trial in the UK, but we would stress the urgent need to establish such a trial quickly so that the NHS is ready to deliver a national lung cancer screening programme when the techniques are fully appraised.

UKLCC CALL FOR ACTION: We urge the UK Governments to implement a lung cancer screening pilot programme now.

Improving public awareness and understanding

Symptom awareness and early detection are crucial to diagnosing lung cancer when it is at a stage when treatment is most likely to be effective. Improving public and health professionals' awareness of the disease is one of the UKLCC's core objectives.

Some groups are known to be at increased risk, for example long-term smokers and patients with Chronic Obstructive Pulmonary Disease (COPD) – a disease in which the lungs are damaged, making it difficult to breathe. Targeted education and high-quality information provision is especially important for these people, though everyone needs to be aware of the signs and symptoms of lung cancer.

We know that many lung cancer patients delay in seeking a diagnosis, believing that they simply have a 'smoker's cough' or because they feel a sense of guilt in that, by smoking, they have in some way brought their illness on themselves. It is important that the message is sent out that any persistent cough (whether the sufferer is a smoker or not) needs to be checked out. Patients should feel empowered to ask questions of their doctor, and raise any concerns. They should be encouraged to think in advance about their consultation in order to get the best from it.

Patients are known to seek advice from five or six sources before visiting primary healthcare. A range of healthcare professionals, including pharmacists and nurses, therefore have an important role in encouraging early presentation and referral to GPs for symptomatic patients.

UKLCC CALL FOR ACTION: We call on the UK governments and health authorities to support primary care organisations in putting local strategies and initiatives in place to improve professional and public symptom awareness.

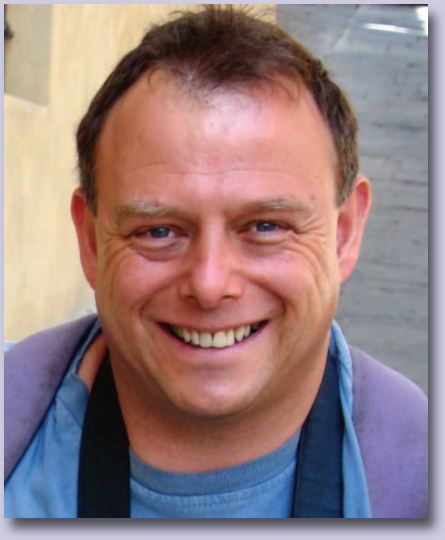
Case Study - Improving Symptom Awareness

Patients with lung cancer continue to be referred to hospital in the advanced stage of their disease. In an attempt to address this, the lung cancer nursing team at Glenfield Hospital, Leicester is undertaking an audit to identify and work with areas of high incidence and late-stage referral.

Lung cancer nurse specialist, Jane Brunskill says:

We're mapping the incidence and stage of patients being referred to our respiratory team from GP practices throughout Leicester and Leicestershire. By identifying areas with high incidence, we can then target specific education and training for GPs and practice nurses. This will help them being alert to symptoms that could indicate the presence of lung cancer in high risk patients. There are real benefits to taking messages about symptom awareness out to the general public and also to healthcare professionals. We want patients to seek help early on and all members of the primary care team to be alert to the high risk groups for developing lung cancer. We hope this will drive early referrals, giving us the best chance of treating patients successfully.

Case Study – Empowering Primary Care



Dr Steve Holmes is a GP with a special interest in lung cancer and a member of the General Practice Airways Group. He believes that better communication between GPs and their patients could help to improve diagnosis. He says:

It would upset me to think that a patient might be suffering symptoms, worrying about them, and not go to their GP to get them checked out. If you're worried about your health – go and see your GP. Early presentation really does make a difference with lung cancer.

But it is a partnership. Primary healthcare professionals also need to be alert to the signs and symptoms of lung cancer, especially if the patient in front of them is likely to be at high risk – has COPD or is a long-term smoker, for example. Further research into identifying high risk patients would be a big plus.

Primary Care

The delay between a patient presenting with symptoms and a diagnosis being confirmed must be tackled. The average delay before a patient presents to primary care is in the region of seven months; between first seeing a primary care clinician and first visiting a colleague in secondary care professional is around six weeks and a further 14 weeks before a diagnosis is made.[5]

Despite lung cancer being the most common cancer, most doctors may only see one or two cases a year, compared to many coughs and other respiratory problems. We need to find methods to help healthcare professionals stratify risk, identify high risk patients – for example, those with chronic obstructive pulmonary disease - and refer appropriately. A range of tools for risk stratification or symptom identification should be developed, including use of questionnaires for patients while waiting in GP surgeries.

'Significiant Event Audits' can be used to track how many times patients seek advice before a diagnosis is made to help identify common patterns and tell tale signs. Such audits can be relatively easy to initiate – practices undertaking the Quality Practice Award have undertaking significant event audits of cases of diagnosed cancers already. The UKLCC believes that audits of lung cancer diagnoses should be rolled out more widely to help understand the barriers to early diagnosis and inform best practice. From these, a risk assessment tool (similar to the adjuvant risk assessment tool for breast cancer) could be developed to help GPs assess the need for referral.

In addition, primary healthcare professionals have an important role in post-diagnosis support and care. It is vital that hospital test results are communicated back to primary care quickly to enable GPs and practice nurses to give appropriate support.

UKLCC CALL FOR ACTION: We call on the health departments in all UK administrations to support research into risk stratification and patterns of presentation, and to encourage primary care organisations and healthcare professionals to engage with these.

[5]Koyi H, Hillerdal G & Branden E. Patient's and doctors' delays in the diagnosis of chest tumours. Lung Cancer 2002; 35:53-7

Information and support

A cancer diagnosis can be a shattering experience for any patient. For most lung cancer patients, the diagnosis is likely to come with a poor prognosis and the recognition that they may have relatively little time left to live.

It is therefore essential that lung patients are provided with information and support from the first investigations, and that communication around diagnosis, treatment, clinical trials and palliative care is made in a particularly sensitive way. Non-clinical information, for example about financial and practical support, is also very important.

The lung cancer specialist nurse is vital as a consistent source of information and support, but patients are also likely to seek advice from other sources, including patient support groups, information centres and charities. These all have important roles to play.

The UKLCC supports the idea of an 'information prescription', given to the patient at diagnosis and at other key points in their cancer journey in order to provide them with signposts to sources of information and support. 'Power questions' and decision making tools have been found to be useful in making sure that patients ask all the questions they need in a dialogue with their consultant or nurse and to help ensure they at the centre of the decision making process. However many patients will need additional support and advice to fully understand and act upon the information they are given.

The patient experience should be monitored on a regular basis to assess and improve the performance of cancer services, with the results made accessible to the public and acted upon by cancer service providers. The new NHS levers – most notably commissioning, the tariff and the Quality and Outcomes Framework – should be used to incentivise improvements in the patient experience.

UKLCC CALL FOR ACTION: The UK governments must ensure lung cancer patients feel informed about their disease and the support available, and empowered to make decisions about their treatment options in partnership with health professionals.

Patient Story – Wilma Kennedy

Despite having never smoked, Wilma Kennedy (46) was diagnosed with brain cancer and tumours in both of her lungs in November 2005. Wilma says:

I never imagined I'd have to worry about lung cancer – I never smoked or worked in a smoky atmosphere, or was a regular pub or bar-goer. But in 2005 I got the devastating news that I had a brain tumour - it had started with tumours in my lungs.

I've had radical chemotherapy and radiotherapy, and – fortunately – my lung cancer seems to be responding at the moment. I am a positive person and enjoy every day of my life with my wonderful family – even more so now. I'm speaking out about lung cancer to give hope to other lung cancer sufferers out there.

Case Study – Improving the Patient Journey

Lung cancer services in the Birmingham Heartlands Hospital have been reconfigured to introduce a Lung Investigation Day, held two days before each MDT meeting. The patient can see the chest physician, radiologist and nurse specialist and have all necessary tests on a single day. Test results are obtained within 24 hours and discussed by the MDT, leading to a swift diagnosis and treatment plan. This has dramatically speeded up the patient journey, reduced patient anxiety and improved patient outcomes, without incurring extra cost to the NHS.

Richard Steyn, Consultant Surgeon and UKLCC clinical partner says:

In the bad old days, weeks could be wasted in writing letters, requesting tests and calling the patient back to hospital several times. Now, a well-developed pathway supports our excellent MDT.

Everything is co-ordinated and dealt with swiftly, and the feedback from our patients is that this is infinitely better for them. We've dramatically improved the quality of our service, at no cost at all.

Diagnosis and staging

In addition to early reporting of symptoms and speedy referral, rapid access to diagnostic technology is essential if early diagnosis is to be achieved.

There is a need for faster and wider access to chest X-rays for initial diagnosis. The UKLCC supports walk-in access to chest X-rays and believes that commissioners must be encouraged to speed up access to all forms of diagnostic testing.

Careful staging of lung cancer patients is essential for optimum treatment. Wider access to PET-CT scanners would enable accurate staging of the disease. Increased use of these would indicate which patients are candidates for radical treatment and lung resection, as well as those who should progress straight to radiotherapy, chemotherapy or palliation. Other newer diagnostic & staging techniques (eg non-surgical mediastinal node sampling, thoracoscopy) are now of proven benefit and provision must be made to make these widely available.

Additionally the interpretation and reporting of results could be significantly improved. Interpreting chest x-rays and particularly CT scans is a highly skilled role and the UK has too few specialist thoracic radiologists. There should be 100% reporting of chest x-ray results, with rapid referral to a specialist Multi Disciplinary Team (MDT) for any x-ray which raises the possibility of lung cancer. Once a diagnosis has been made, results should also be rapidly reported to the GP, to ensure they can provide appropriate support.

UKLCC CALL FOR ACTION: The health departments in all UK administrations and the commissioners of cancer services should demand that all patients where lung cancer is suspected are referred directly to a highly specialised rapid access clinic which is part of an MDT which has timely access to the appropriate diagnostic and staging tools.

Treatment

The strategies for making a difference to one-year survival as opposed to five-year survival will need to be different, but the bottom line is that numbers of patients receiving active treatment needs to be radically increased. Currently, less than one in ten lung cancer patients survive for five years, often the point in time at which disease is regarded as 'cured'. Doubling the number of patients surviving to five years (from 3,700 to some 7,400) would require a significant increase in the numbers of patients receiving surgery for their disease. This has been shown to be possible in a UK setting.[6]

Wider access to PET-CT scanning to swiftly and accurately stage the disease would enable identification of potentially operable lung cancers. These patients should be quickly routed to specialist lung cancer surgeons, with inter-region referrals for difficult cases. In 2005, only 9% of lung cancer patients in England were treated with surgery[7], and this is well below international standards. Hospitals vary considerably in their resection rates and the follow up treatment that they offer. Any hospital performing lung cancer operations should have a full-time thoracic surgeon. The UKLCC calls for an audit of national surgical practice to identify centres of best practice, so that their processes and experience can be shared. 'Streaming' patients, referring between regions and getting them quickly into centres of excellence would also help to improve outcomes.

Improving one-year survival is likely to be more of an evolutionary process resulting from a series of incremental advances in the delivery of care, chemo- and radiotherapy techniques. This challenge cannot be underestimated; half of all lung cancer patients die within six months of diagnosis and only one in four will live to one year. In 2005, only 42% of lung cancer patients in England had any specific anti-cancer treatment (i.e. surgery, chemotherapy or radiotherapy)[8]. Again this rate varies widely across the UK and is very low by international standards. We would like to see many more patients receiving appropriate, active treatment. Efforts also need to be made in developing treatments that improve the quality of life for patients, as well as extending survival.

In addition, the Improving Outcomes Guidance (IOG) or NICE guidance should be revised to include many more service delivery and patient-centred measures, and commissioners should be provided with a set of key questions/guidelines to assist them in commissioning a high standard of care for lung cancer patients.

UKLCC CALL FOR ACTION: More lung cancer patients should be considered for active treatment, with all centres learning from those where innovative and aggressive cancer management is bringing about better patient outcomes.

[6]Martin-Ucar AE, Waller DA, Atkins JA, et al. 'The beneficial effects of specialist Thoracic Surgery on the resection rate for non-small cell lung cancer.' Lung Cancer, 2004; 46: 227-232

[7]National Lung Cancer Audit: Report for the audit period 2005. The Information Centre for Health and Social Care, 2006. www.ic.nhs.uk

[8]Ibid

End of life care

Despite current best efforts, around half of all lung cancer patients will die within six months of diagnosis, and the vast majority will die within five years. Not all patients and carers want to discuss end of life care. However, a lack of opportunities to discuss the implications of possibly being in the last year of life can seriously affect quality of life for both the patient and their carer while also placing unnecessary additional burden on the NHS.

Key to good end of life care is having several opportunities to have a 'what if' conversation. This needs to start by raising awareness among target professionals (oncologists and haematologists) around 'triggers' for flagging a patient with unrecognised end of life care needs. This could be done by recording whether the health professional would be surprised if the patient died within a year. Flagged patients should then be mentioned in hospital and primary care MDT meetings so that 'what if' discussions take place and patients are on primary care supportive registers. 'What if' conversations should also trigger other auditable activities – for example financial support advice, carer information, Out Of Hours handover – either in primary or secondary care.

Surveys suggest that the majority of cancer patients would choose to die at home, but only around a quarter are able to do so. The UKLCC welcomes the Government's commitment to doubling the funds allocated to the care of terminally ill patients, and hopes that this will enable an expansion in the range of palliative care options open to patients.

Information about palliative care must be provided to lung cancer patients and their families, in a sensitive, timely and appropriate way, so that they can make decisions about their care options. Financial and legal advice and support is also important, so that patients can make provision for loved ones.

UKLCC CALL FOR ACTION: The UKLCC calls on primary care organisations to examine the provision they make for palliative care, and ensure that all lung cancer patients have access to the information and support services they need.

Managing care

NICE recommends that all lung cancer patients are treated within a multi-disciplinary team (MDT). The UKLCC support this but understand that that there is enormous variation in the quality, scope and effectiveness of lung cancer MDTs. Some problems, for example, the timing, chairing and audibility of meetings, should be easy to resolve. Templates for MDT training programmes already exist in the areas of prostate and bowel cancer, and should be applied in lung cancer.

Other issues, however, are harder to resolve. There is evidence that clinicians, especially surgeons, are spread too thinly and this means that MDTs may only benefit from one surgical opinion or in some cases miss out altogether. The recent round of Cancer Peer Review in England has shown that in around half of the recent lung cancer MDTs many key specialists are able to attend less than 50% of the meetings.[9] This suggests a need for fewer MDTs, concentrated round centres of excellence. Better use should be made of technology, including video- and tele-conferencing to assist with this.

The UKLCC believes that the quality of MDTs can and must improve: they should be better attended, more focussed and better run. This may well mean a reduction in the number of MDTs, so we support better use of technology to enable those who are remote from centres of excellence to take part in MDT meetings via video- or tele-conferencing.

Guidelines on how to operate a successful MDT and training for those involved should be implemented to ensure a competent national standard. The UKLCC also believes that the British Thoracic Society Guidelines on Fitness for Surgery should be revised to reflect recent developments.

UKLCC CALL FOR ACTION: Every MDT should be able to demonstrate that it is meeting national standards, with specialised representatives of each of the key disciplines present at every meeting. High quality data collection should be a necessary part of their activity.

Capacity and Workforce issues

In lung cancer, although the efforts to reduce smoking prevalence will eventually cause a reduction in cases, we will still see many thousands of people being diagnosed with the disease in the years to come. Demands on cancer services are therefore likely to increase in the face of current shortages in key disciplines, including oncology, specialist nursing, radiology, pathology and allied health professionals.

Many reports indicate that specialist thoracic surgeons achieve better outcomes than generalists for lung cancer surgery, and this is critical to improving survival rates. However, at present in the UK, a shortage of specialist thoracic surgeons mean that around 60% of thoracic surgery is carried out by cardio-thoracic surgeons who work across two specialties. Encouraging more surgeons to specialise in thoracic and lung cancer surgery will be critical in tackling this.

Worryingly, the UKLCC has intelligence that the roles of lung cancer nurse specialists – hugely valued by patients and their families and a vital source of information, advice and support - are under threat. Urgent steps must be immediately taken to safeguard these. The Coalition strongly defends and supports the role of the cancer nurse specialist and calls on the Secretary of State for Health and Chief Nursing Officer to ensure that these valued health professionals continue to grow in numbers and are available to all lung cancer patients.

UKLCC CALL FOR ACTION: The health departments in all UK administrations should undertake a capacity review and deliver a workforce strategy to meet it, taking account of projected increases in demand and addressing current shortages in all key disciplines, including specialist surgery and specialist nursing.

Case Study – Improving Specialist Nursing

Maria Guerin, Chair of the National Lung Cancer Forum for Nurses, is a specialist lung cancer nurse based in University Hospital Aintree and a UKLCC clinical partner. Annually she supports in excess of 300 newly diagnosed lung cancer patients and patients undergoing investigations the Liverpool area. Maria says:

Undergoing investigations and subsequently receiving a lung cancer diagnosis can be shattering. Specialist nurses are there for patients from the point of diagnosis (and often prior to this during the initial investigation process) providing information, advice and support for both patient and their families.

It's hard to demonstrate the value, effectiveness and quality of the work in facts and figures, but the patients tell us the difference it makes to their journey is without precedence. They gain strength and comfort from knowing that there is a specialist nurse there to support them every step of the way.

Sadly we just don't have enough specialist nurses, meaning that many patients around the country miss out on this important aspect of their care. By rights, every patient should have access to a specialist nurse as a fundamental part of their care.

Research

Lung cancer receives less research funding than other cancers, relative to both incidence and mortality. In 2005, only 3.9% of research targeted at specific cancers was spent on lung, despite the fact that the disease causes more than one in five cancer deaths.

UKLCC partners are already at the forefront of lung cancer research, and fund a large proportion of the UK's investment in the area. The UKLCC strongly believes that the site specific research spend on lung cancer should be increased with investment in screening and early diagnosis and a focus on reducing the risks of lung cancer in high-risk populations. This should include a greater number of, and greater access to, clinical trials. Another area in need of attention is improving quality of life and addressing morbidity arising as a result of lung cancer treatment.

However, in order to generate better, high quality research, we need to revitalise the lung cancer research community. Historically there has been a sense of nihilism in lung cancer research, but steps are being taken to dispel this and attract a new generation of inspired and inspiring researchers into the area. Making strides in lung cancer research will depend on having the finest research minds focussed on investigating every angle, from prevention and detection to discovery of new targets for treatments.

UKLCC CALL FOR ACTION: The UK governments to fund more research into the early detection and diagnosis of lung cancer and calls on the lung cancer research community to raise the bar – generating further high quality research into the prevention, detection and treatment of the disease and expanding access to clinical trials.

Data collection – underpinning the knowledge base

Understanding what is happening in clinical practice and how this is affecting patient outcomes depends on having first-class data collection. The National Lung Cancer Audit (LUCADA) is one of the first national comparative audits of cancer services. It is commissioned by the Healthcare Commission, and managed by the NHS Information Centre in partnership with the Royal College of Physicians.

National comparative audit as exemplified by LUCADA aims to help managers and clinicians asses both the quality of cancer care and patient outcomes delivered by their teams and is the essential first step in efforts to improve the services. The data collected is already providing valuable insights into regional and national performance and will, in time, provide the basis for much of what patients will need to know about their local services.

To enable the highest quality and most meaningful information to be available, it is essential that cancer centres are required to collect the data necessary to make such analyses possible. Commissioners should insist on this as part of their planning processes

UKLCC CALL FOR ACTION: To ensure the high quality data needed for planning and service improvement, primary care organisations should participate in data collection for national audits – and be held to account if they fail to submit their data.

Case Study - Improving Lung Cancer Research

Professor Stephen Spiro is a respiratory physician and lung cancer researcher at University College Hospital London. He believes that the historic nihilism in lung cancer research is being turned around with renewed optimism. He says:

As a researcher and a clinician, I see both sides of the story. Traditionally, lung cancer has been underfunded, and relatively few researchers have wanted to go into the area. But we're gradually making improvements, and I have more options to offer the patients in my clinics. These are the successes that will hopefully encourage more research.

The promise of earlier detection and better treatment of lung cancer – and therefore improving lung cancer survival - lies in research. If I were Secretary of State for Health, I'd be asking the Treasury for an immediate Government investment of £5m to allow me to double current research spend on the disease.

What is the UK Lung Cancer Coalition?

The UK Lung Cancer Coalition is a coalition of the leading charities, clinicians, health professionals and healthcare companies with a commitment to lung cancer issues. Its members include:

Healthcare professionals

Dame Gill Oliver, UKLCC Chair

Dr Mick Peake, Glenfield Hospital, Leicester

Dr Stephen Falk, Bristol Haematology and Oncology Centre

Prof Stephen Spiro, University College London Hospital

Dr Richard Steyn, Birmingham Heartlands Hospital

Dr Roger Vaughan, Birmingham Heartlands Hospital

Dr Stephen Holmes, GP

Gilmour Frew, Cancer Services Collaborative Improvement Partnership

Liz Darlison and Susan Cowdy, representatives of the National Lung Cancer Nurses Forum

Voluntary organisations

British Lung Foundation, Secretariat

Cancer Black Care

Cancer Research UK

Cancerbackup

General Practice Airways Group

Macmillan Cancer Support

Marie Curie Cancer Care

Roy Castle Lung Cancer Foundation

Tenovus

The UKLCC is funded by its members, who are bound by a funding and governance policy. The member healthcare companies and charities provide financial grants and grants in kind to achieve the UKLCC's stated goals.

Details of our members, governance, aims and objectives can be found on our website at: www.uklcc.org.uk.

Healthcare companies

AstraZeneca

GE Healthcare

Lilly UK

Pierre Fabre

Roche Products

Sanofi-aventis

Unisoft Medical Systems

Contacting UK Lung Cancer Coalition

The UKLCC is keen to engage and work in partnership to bring about improvements in the lung cancer picture.

If you would like more information on this report or any aspect of our work, please contact the UKLCC's secretariat, which is provided by the British Lung Foundation. The British Lung Foundation can be contacted on tel. 020 7688 5555 or email. uklcc@blf-uk.org.

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