

## UNITED KINGDOM LUNG CANCER COALITION 2007 REVIEW

### ABOUT THE UKLCC

The United Kingdom Lung Cancer Coalition (UKLCC) is a powerful partnership of the leading lung cancer charities, clinicians, healthcare professionals and healthcare companies with a commitment to lung cancer issues. The UKLCC is the nation's largest multi-interest group in lung cancer, working to bring lung cancer out of the shadow.

#### Our challenge

Lung cancer is the country's biggest cancer killer. In the UK, someone dies from lung cancer every 15 minutes. Despite some recent improvements in service provision, there are still wide variations in standards across the country, including diagnosis, treatment and care for lung cancer patients.

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

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

### INTRODUCTION

2007 was a fantastic year for the UKLCC. We held our inaugural conference with clinical partners from across the country, which formed the basis of our new strategy: *Lung Cancer Plan: improving lung cancer survival in the UK*. We were also busy in Westminster; we hosted a parliamentary reception to highlight the importance lung cancer issues, organised a roundtable meeting with MPs, clinical nurse specialists and their patients and met with the Health Minister to discuss lung cancer research. Our lung cancer champions were also busy tabling parliamentary questions and visiting local hospitals to learn more about the patient pathway.

We plan to build on the success of 2007 by focusing on three key strands from the Lung Cancer Plan: awareness; workforce and capacity; and treatment and data. I very much look forward to working with you over the coming year to deliver on some key objectives in these areas and move us closer to achieving our vision of improved lung cancer survival.



Dame Gill Oliver  
Chair, UK Lung Cancer Coalition

## POLITICAL ENGAGEMENT

### LUNG CANCER CHAMPIONS

The UKLCC is lucky to enjoy the support of many politicians, but we work especially closely with a small group of 'lung cancer champions'. Drawn from across the UK, our parliamentary champions help us by tabling parliamentary questions and Early Day Motions, and raising lung cancer issues during debates. Our champions have also undertaken hospital visits to meet with some of our clinical partners working at the forefront of cancer services. These visits are an opportunity to learn about some of the achievements and challenges facing lung cancer treatment and care. In 2007 the UKLCC organised the following visits:

- Andrew Lansley MP (Shadow Secretary of State for Health) – Dr Robert Rintoul, Papworth Hospital
- Robert Syms MP – Dr Virginia Lawrence, Poole Hospital
- Rob Wilson MP – Dr Andrew Zurek, Royal Berkshire Hospital
- Lynne Jones MP – Dr Richard Steyn, Birmingham Heartlands Hospital
- John Leech MP – Professor Nick Thatcher, Christie Hospital, Manchester

We are grateful to all our clinical partners who hosted visits.

### MINISTERIAL MEETING – JANUARY 2007

Representatives from UKLCC met with Lord Hunt, former Minister for Quality at the Department for Health to brief him on lung cancer research issues. The discussion covered areas from new clinical trials being initiated, to the promise of biomarkers and screening programmes, to the need for better research into patient outcomes. The Minister agreed to raise lung cancer research at his forthcoming meeting with the Medical Research Council.

### UKLCC PARLIAMENTARY RECEPTION – JULY 2007

Following the UKLCC's inaugural clinical conference, delegates attended a special Parliamentary Reception. Norman Lamb MP, the Liberal Democrat Health Spokesperson, gave a welcoming address followed by speeches from lung cancer patients, the UKLCC's chair, Dame Gill Oliver, and the Health Minister, Ann Keen MP. It was the Minister's first public engagement in her new role. A number of other MPs attended and signed a pledge board supporting the UKLCC's objective of doubling lung cancer survival.

### ALL PARTY PARLIAMENTARY GROUP ON CANCER – JULY 2007

The UKLCC were invited to speak at a meeting of the All Party Parliamentary Group on Cancer, focusing on the most common cancers, including lung. Dame Helena Shovelton, UKLCC Vice-Chair, presented the UKLCC's key messages on lung cancer to assembled Parliamentarians, and answered questions from the All Party Group's members. The meeting was very well attended by parliamentarians and stakeholders, and a terrific opportunity to raise awareness of lung cancer issues and the work of the UKLCC.

### LUNG CANCER CLINICAL NURSE SPECIALISTS – NOVEMBER 2007

The crucial role played by Clinical Nurse Specialists (CNS) in patient care was a key priority area identified by Clinical Partners and included in the Lung Cancer Plan. As a result the UKLCC along with the NLCFN (National Lung Cancer Forum for Nurses) organised a roundtable meeting in Westminster, sponsored by lung cancer champion and opposition health spokesperson Anne Milton MP. Parliamentarians met with nurses from NLCFN, patients and representatives from UKLCC – Dame Gil Oliver and Professor Stephen Spiro - to raise awareness of the significant role that CNS play in the patient journey and highlight the need to

safeguard and develop their roles. The UKLCC will continue to campaign in this area in 2008.

## CLINICAL ENGAGEMENT

### CLINICAL CONFERENCE – JULY 2007

The UKLCC Clinical Sub-Group and its Chair, Dr Mick Peake, feed through their views on lung cancer policy on a regular basis, helping to formulate the UKLCC's policy statements and inform its campaigning work.

For the first time, UKLCC Clinical Partners from across the UK and representing a variety of specialties, met for a day in Westminster to share views and expertise and begin formulating a strategy to take lung cancer policy forward. There was consensus on 12 key areas where action was urgently needed to improve lung cancer survival. The Clinical Partners' views became the basis for the UKLCC's first Lung Cancer Plan (see below), which has set the direction of the UKLCC's forthcoming work programme. After a successful first conference, we hope that we will be able to bring together Clinical Partners for an annual clinical conference.

## LUNG CANCER POLICY

### LUNG CANCER AWARENESS MONTH – NOVEMBER 2007

November is Lung Cancer Awareness Month and every year UKLCC members undertake joint and individual activity to put lung cancer in the spotlight. As the UKLCC's contribution, the Coalition put together a pharmacy toolkit, to support and encourage pharmacists to engage with their local MPs. By inviting their local MP to a photocall, pharmacists were able to highlight the important role of the pharmacist in helping to raise awareness of lung cancer signs and symptoms and encouraging patients with potential symptoms not to delay seeking advice from their GPs. The toolkit was very well received and photocalls were secured with a number of MPs, including Oliver Heald MP, James Clappison MP, Mike Hancock MP, Lorely Burt MP and David Clelland MP, generating significant local press coverage.

### CANCER CAMPAIGNING GROUP WHITE PAPER – FEBRUARY 2007

The UKLCC sent a detailed response in to the Cancer Campaigning Group's White Paper: '*Getting it right for people with cancer – what the voluntary sector wants from the cancer reform strategy*'. In addition to supporting many of the calls that the UKLCC made, two UKLCC case studies were included in the CCG's final report. Birmingham Heartlands Hospital featured for their work in enhancing the multi-disciplinary team model and the National Lung Cancer Audit was cited as an example of clinical data providing valuable insights into regional and national performance. Copies of the White Paper can be downloaded online at: [www.cancercampaigninggroup.org.uk](http://www.cancercampaigninggroup.org.uk). Importantly, many of the UKLCC's calls were also carried through into the final Cancer Reform Strategy, published at the end of 2007.

### UKLCC LUNG CANCER PLAN – NOVEMBER 2007

Following from the success of the Clinical Partners Conference, the UKLCC published the *Lung Cancer Plan: improving lung cancer survival in the UK*. The twelve point plan recognises some of the progress made and highlights priority areas for tackling lung cancer, namely:

- prevention
- screening
- awareness
- primary care
- information and support
- diagnoses and staging
- treatment
- end of life care
- managing care
- workforce capacity
- research
- data collection

The Plan was sent to key stakeholders including parliamentarians, Cancer Networks and Department of Health officials. The Plan was warmly welcomed by the National Cancer Director, Professor Mike Richards, and Health Minister, Ann Keen.

Copies of the Lung Cancer Plan can be downloaded online at:  
[http://www.uklcc.org.uk/pdf/PRX2651\[1\].UKLCC.brochure.pdf](http://www.uklcc.org.uk/pdf/PRX2651[1].UKLCC.brochure.pdf)

## MOVING FORWARD IN 2008

### LUNG CANCER AWARENESS

In 2008 the UKLCC will be focusing on three strands of activities drawn from the Lung Cancer Plan: awareness; workforce and capacity; treatment and data collection. On the first strand, our aim is to create greater public, professional and political awareness of the disease. The UKLCC will conduct an attitudes survey to update our evidence on attitudes to lung cancer. UKLCC members are also contributing to the DH's plans for Lung Cancer Awareness Month and the UKLCC will also be organising its own activities for November.

### WORKFORCE AND CAPACITY

#### Clinical Nurse Specialists

As agreed by the UKLCC Board a key aspect of 2008 will be working with the National Lung Cancer Forum for Nurses (NLCFN) in raising the profile of lung cancer clinical nurses specialists and bolster the critical importance of their role in the care of lung cancer patients with key policy makers. We are calling on parliamentarians and policy makers to support specialist nurses, and where necessary campaign to make sure that their roles are safeguarded, so they can continue to provide the specialist support that lung cancer patients and their families need.

The UKLCC will be organising a 'Westminster Fly-In' for lung cancer nurse specialists from every cancer network in Lung Cancer Awareness Month in November. Building on the successful roundtable MP hosted by Anne Milton MP last year, this will allow MPs to meet a local nurse and discuss some of the issues around their roles. The event will also help to raise lung cancer awareness and the photographs and press releases will be used by MPs in their local press.

#### UKLCC Symposium at the Liverpool Lung Cancer Research Conference

Thanks to the help from a number of sponsors, the UKLCC will be able to play an active role at the Liverpool Lung Cancer Research Conference. We look forward to a lively and informative debate on whether lung cancer MDTs are fit for purpose, which will help raise issues around MDTs and their current role and capacity

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## Conservative Party Conference

The UKLCC will undertake a meeting programme at the Conservative Party Conference. The conference runs from Sunday 28 to Tuesday 30 September. Dr Richard Steyn, Consultant Thoracic Surgeon and UKLCC clinical partner based locally at Birmingham Heartlands Hospital, has kindly agreed to attend one day of Conference on behalf of the UKLCC. He will be attending with a clinical nurse specialist.

The meeting programme aims to:

- Raise awareness of the need to secure and expand the lung cancer workforce, and particularly numbers of specialist lung cancer surgeons and nurses
- Secure new advocates for lung cancer issues in preparation for Lung Cancer Awareness Month
- Engage with key policymakers in a resurgent Conservative Party

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## TREATMENT AND DATA COLLECTION

### National Lung Cancer Audit

A major theme of the work programme includes improving data collection through the national audit, which is crucial to improving service planning, provision and standards. The UKLCC wrote to those Trusts who performed poorly in last years' National Lung Cancer Audit to encourage them to submit more robust data for this year. We also wrote to the Cancer Networks and Strategic Health Authorities who oversee these Trusts and to their local MPs to encourage more comprehensive data collection.

We have had replies from 14 health authorities. Some of these have raised technical questions regarding submitting data which we have forwarded to the people leading the audit, but others have replied with supportive messages for participation in this year's audit.

We are particularly grateful to Henry Bellingham MP, Paul Goggins MP, John Leech MP, Alison Seabeck MP and Ann Widdecombe MP who have all written to their local Trusts to encourage them to participate in the audit. We look forward to seeing the results of the audit in due course and hopefully increased participation by Trusts this year.

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## UKLCC MEMBERSHIP

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### LEADERSHIP

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 is chaired by Dame Gill Oliver
- The Vice-Chair is Dame Helena Shovelton, British Lung Foundation
- The Clinical Reference Group is chaired by Dr Mick Peake, National Clinical Lead for Lung Cancer, Glenfield Hospital, Leicester
- The Communications Sub-Group is chaired by Jill Morrell, British Lung Foundation

## OUR MEMBERS

### 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  
Nicola Bell and John White, representatives of the National Lung Cancer Nurses Forum

### Voluntary organisations

British Lung Foundation, Secretariat  
Cancer Black Care  
Cancer Research UK  
General Practice Airways Group  
Macmillan Cancer Support  
Marie Curie Cancer Care  
Roy Castle Lung Cancer Foundation  
Tenovus

### Healthcare companies

AstraZeneca UK Ltd  
GE Healthcare (retired end of 2007)  
Lilly UK  
Pierre Fabre  
Roche Products  
Sanofi-aventis  
Unisoft Medical Systems

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](http://www.uklcc.org.uk).

## CONTACT US

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 about any aspect of our work, please contact the UKLCC's secretariat, which is provided by the British Lung Foundation.

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