

UKLCC Annual Report 2008

Who we are

The United Kingdom Lung Cancer Coalition (UKLCC) is a partnership of charities, clinicians, senior NHS professionals and healthcare companies with a commitment to double lung cancer survival. It is the nation's only multi-interest group in lung cancer.

The UKLCC is primarily a campaigning organisation. Information and support for people affected by lung cancer can be found separately by contacting the charity members of the UKLCC, whose details are available via our website www.uklcc.org.uk

Introduction from Dame Gill Oliver, Chair of the UKLCC



2008 has been a very full and busy year for the UK Lung Cancer Coalition. Thanks to the hard work, commitment and enthusiasm of members we have achieved an enormous amount. You will read more about the various projects in the main body of the report but I would like to highlight one or two areas for you.

Internally we have spent time on governance issues making sure that we have all the correct policies and procedures in place and that our meetings and groups are properly constituted. We were able to formalise our agreement with BLF for the provision of our Secretariat and this has paid huge dividends in the management of our activities and meetings.

Public affairs and public relations are crucial to our success and we have worked hard to ensure that expert and professional services are included in our projects and activities.

The unique nature of UKLCC, a partnership between clinical professionals, the charity and voluntary sector and industry has enabled us to bring a wide range of skills and expertise to our various workstreams. It was particularly encouraging to see the numbers of MPs who responded to our invitation to meet Lung Cancer Specialist Nurses from their own constituencies at the Westminster Nurse Fly-in. In the discussions, nurses were able to bring elements of their role to life and so MPs and the Health Minister, Ann Keen, spent much longer with us than we would normally have expected given the many demands on their parliamentary time .

Following the publication of the 2nd National Lung Cancer Audit we were greatly encouraged by the very positive responses to our letters to hospitals, Primary Care Trusts (PCTs) and MPs. Their commitment to improving data submission to future audits and to encouraging local lung cancer developments was testimony to the lobbying and campaigning of our members.

Also I cannot miss including very sincere congratulations to all those who played a part in the UKLCC's success at the Communique Awards. The Award which was entered jointly between the UKLCC and the National Lung Cancer Forum for Nurses was for "Best Opinion Leader/Advocacy Development".

Our campaign for Lung Cancer Awareness Month 2008 was described by the judges as 'an example of a really impressive programme which empowered trained nurses to be successful advocates, this really did the job - it put the role of these specialist nurses firmly on the agenda'.

The hard work and achievements of 2008 have provided a firm foundation on which to plan and build our future work. We still have much to do if we are to double the survival rates for lung cancer. By working together we really can make a difference, and the UKLCC is in just the right place to do it.



Dame Gill Oliver, Chair of the UK Lung Cancer Coalition

Our challenge

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

In addition, UK lung cancer survival rates lag well behind the European average, despite our relatively high national expenditure on health services. The average five year survival rate in the four nations is 8.95% [England (8.6%), Scotland (8.0%), N Ireland (10.2%) and Wales (9.0%)] compared to 12.3% in Europe.¹

The UKLCC believes that much 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 lung cancer survival

In order to achieve this goal we have set ourselves 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 among non-specialist healthcare professionals

¹ Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995–99: results of the EURO CARE-4 study Franco Berrino, Roberta De Angelis, Milena Sant, Stefano Rosso, Magdalena The Lancet Oncology, Volume 8, Issue 9, Pages 752 - 753, September 2007

- Improve lung cancer services in the UK
- Increase research funding for lung cancer
- Raise awareness of recent achievements in the management of lung cancer

The UKLCC 12 point Lung Cancer Action Plan

In November 2007, the UKLCC published its 12 point lung cancer action plan - with calls for action which we believe would make a real difference for lung cancer patients. The action plan covers lung cancer prevention; screening for lung cancer; awareness of the signs and symptoms of lung cancer; primary care; information and support for lung cancer patients; the diagnosis and staging of lung cancer; its treatment; end of life care; workforce capacity; the management of care; research and data collection. It can be accessed on our website: www.uklcc.org.uk

The UKLCC firmly believes that raising standards of care across the NHS up to those in operation in the best centres would save many thousands of lung cancer patients' lives. We are keen to work with the NHS and Government, patients and carers, industry and voluntary sector to make sure this happens.

What we achieved in 2008

Political Engagement

Parliamentary Champions

The UKLCC is supported by many politicians who have a commitment to ensure that messages about lung cancer - especially the signs and symptoms of the disease and the importance of early diagnosis - reach their constituents. We work especially closely with a small group of lung cancer champions. Drawn from across the UK, our parliamentary lung cancer champions help us by taking action on a number of fronts to raise awareness of lung cancer through - for example - tabling parliamentary questions and early day motions, and raising lung cancer issues during parliamentary debates.

Our lung cancer champions have also undertaken visits to lung cancer centres and met with our clinical partners working at the forefront of cancer services

Our lung cancer champions

Rt Hon John Battle MP	(Leeds West)
Rt Hon Frank Dobson MP	(Labour, Holborn & St Pancras)
Mark Durkan MP	(SDLP, Foyle)
Sharon Hodgson MP	(Labour, Gateshead East & Washington West)
John Leech MP	(Liberal Democrat, Manchester Withington)
Dr Alasdair McDonnell MP	(SDLP, Belfast South)
Anne Milton MP	(Conservative, Guildford)
Madeleine Moon MP	(Labour, Bridgend)
Sir Peter Soulsby MP	(Labour, Leicester South)
Jo Swinson MP	(Liberal Democrat, East Dunbartonshire)
Robert Wilson MP	(Conservative, Reading East)

Raising Awareness

Nurse Fly in - Lung Cancer Awareness Month

The UKLCC believes that every lung cancer patient should have access to a lung cancer specialist nurse. We are concerned to note the severe shortages of and variations in numbers of nurses across the country - at present one in ten lung cancer patients does not have access to a specialist nurse.

To raise awareness of this issue, we arranged for lung cancer specialist nurses from across the UK to meet with parliamentarians and ministers on the eve of Lung Cancer Awareness Month. They called on the Government to stand by their commitment for every lung cancer patient to have access to a specialist nurse.



Maria Guerin, Chair of the National Lung Cancer Forum for Nurses, with Ann Keen MP, Health Minister

The delegation of specialist nurses, led by Maria Guerin, Chair of the National Lung Cancer Nurses Forum visited Portcullis House in Westminster where they were able to meet MPs and peers from their own locality. More than 40 MPs came along to meet their local nurse and discuss the vital role that they play in providing specialised, dedicated care and support for lung cancer patients.



In addition over 80 MPs signed an Early Day Motion tabled in Parliament applauding the work of lung cancer specialist nurses and calling for equal and improved access to lung cancer services across the country, including access to a specialist lung cancer nurse for every patient.

The Nurse Fly In attracted widespread media coverage and its success has built a platform for future activity across Westminster and Whitehall as we campaign for greater access to lung cancer specialist nurses across the UK. In recognition of the success of this campaign, the UKLCC and the National Lung Cancer Forum for Nurses were subsequently awarded "Best Opinion Leader / Advocacy Development" at the 2009 Communique Awards.

Treatment and Data Collection

National Lung Cancer Audit

The 2nd National Lung Cancer Audit (NLCA) annual report was published in December 2007. It contained information about 22,000 lung cancer patients from England and Wales.

For the second successive year, UKLCC undertook an in-depth analysis of the Audit, and used the resulting information to raise issues about lung cancer services with a range of key stakeholders. We wrote to hospitals that provide lung cancer services but had not submitted data to encourage them to participate in the third audit. We wrote to PCTs who commission lung cancer services, and to MPs in whose constituencies Trusts had not submitted data to the audit. Our aim in doing this

was to increase participation in the audit, and hence to reveal trends in service provision and quality.

The English Cancer Reform Strategy pledged to use information to drive up the quality of clinical practice and clinical outcomes. NLCA is a good example of this process at work. The number of patient records covered by the second Audit was nearly 22,000, or 66% of the expected number of cases for the audit period, up from 40% in the previous year.

The UKLCC will continue to utilise the NLCA data to encourage providers and commissioners to improve their local services and make a positive impact on patient outcomes. We hope that still more data will be submitted to the third audit.

Clinical Engagement

Is your MDT fit for purpose?

In July 2008, the UKLCC held a symposium at the International Lung Cancer Conference held at the Liverpool Convention Centre. The aim of the symposium was to review the current status and impact of Multi-Disciplinary Team (MDT) working in lung cancer care in the UK by inviting a range of speakers to give their perspectives and recount their experiences of MDTs.

Speakers included Gill Oliver, Chair of the UKLCC, Mick Peake, Chair of the UKLCC Clinical Reference Group and DH National Lung cancer Lead; Cheryl Cavanagh, MDT Lead for the Department of Health and National Cancer Action Team; Trevor Rogers, Consultant in General and Respiratory Medicine, Doncaster Royal Infirmary, and Robert Rintoul, Consultant in Respiratory Medicine at Papworth Hospital, Cambridge.

Following the presentations, a debate was held in which key issues in MDT working were raised including their capacity, their structure and size, and their efficacy. A full report of the meeting can be found on our website.

Supporting the role of surgeons

In 2008 we held a meeting with representatives of Presidents of the Royal College of Surgeons and Society for Cardiothoracic Surgery. We wanted to discuss key issues in lung cancer surgery including data collection, variations in resection rates and capacity in specialist thoracic surgery.

We reached agreement on drafting a joint position statement on best practice model for referral, and will be exploring further work with the Royal College of Surgeons during 2009, such as hosting a seminar on improving access to specialist surgery.

Our Plans for 2009

Raising Awareness

In 2009, we aim to continue our track record of raising awareness of the issues surrounding lung cancer by working closely with national media, and by undertaking activities during November's National Lung cancer Awareness Month.

Working with Clinicians

We will review and update our 12 Point Plan in 2009, by working closely with our Clinical Advisers to identify the key priorities for the future.

Continuing to engage with Parliamentarians

Working with our Parliamentary Champions will continue to be a key part of the UKLCC's strategy for raising awareness of lung cancer, and achieving change through national policy development. We feel this is particularly important in the run up to a general election that may see many new faces in our national parliaments.

Treatment and Data Collection

2009 will see the publication of the third annual report of the National Lung Cancer Audit, and will be the first time that data from Scotland has been reported. The UKLCC will be at the forefront of moves to improve participation in the audit and to encourage Commissioners and Trusts to seek ways to raise standards of lung cancer care and hence improve patient outcomes, .

UKLCC Members in 2008

<u>Healthcare professionals</u>	<u>Voluntary organisations</u>
Dame Gill Oliver, UKLCC Chair	British Lung Foundation (Secretariat)
Dr Mick Peake, Glenfield Hospital, Leicester	Cancer Black Care
Dr Stephen Falk, Bristol Haematology and Oncology Centre	Cancer Research UK
Prof Stephen Spiro, University College London Hospital & Royal Brompton Hospital	General Practice Airways Group
Mr Richard Steyn, Birmingham Heartlands Hospital	Macmillan Cancer Support
Nicola Bell and John White, representatives of the National Lung Cancer Nurses Forum	Marie Curie Cancer Care
	Roy Castle Lung Cancer Foundation
	Tenovus
	<u>Healthcare companies</u>
	AstraZeneca UK Ltd
	GlaxoSmithKline
	Lilly UK
	Merck Serono
	Pfizer
	Roche Products

In addition to sponsorship and grants from different or member organisations, core funding for the UKLCC is obtained from membership fees received from pharmaceutical companies. Details of our members, governance, aims and objectives can be found on our website.

Leadership

The UK Lung Cancer Coalition is made up of 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 Advisory Group is Chaired by Dr Mick Peake, National Lead for Lung Cancer, Glenfield Hospital NHS Trust, Leicester
- The Communications Group is Chaired by Nicky Coombes, Cancer Research UK.

Contact the UKLCC

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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