

The History of the
**National Lung Cancer
Forum for Nurses**



Following the Calman Hine Report in 1995 (DOH), which emphasised the potential value of site-specific specialist nurses in improving the care cancer patients received, the number of lung cancer nurses increased significantly. This was further endorsed by the Improving Outcomes in Lung Cancer document (NHSE 1998), which identified lung cancer nurses as a core member of the multidisciplinary team.

Recognising that lung cancer nurse posts had been created with very little strategic planning or forethought into what the role required, a small cohort of Lung Cancer Nurse Specialists employed throughout the United Kingdom got together with Lilly Oncology to identify the needs of lung cancer nurses, with consideration to those who worked in isolation, new to post and performing similar roles. The first National meeting was held in Liverpool and had 40 attendees, these included, Tessa Fitzpatrick, John McPhelim and Gill Walton, who all still support the Forum with as much enthusiasm today as they had at the very beginning.

The 40 attendees unanimously agreed that a national body was needed to provide a voice on strategic and clinical issues and to share best practice and that membership to the Forum be open to any specialist nurse who spends more than 50% of their working week or clinical activities in caring for patients with lung cancer patients. From this meeting the National Lung Cancer Forum for Nurses was established in July 1999 and a committee formed. The first constitution was developed with the objective that the NCFN was to provide a network and support for nurses. This included education, professional development, audit and research. Initially the Forum was free to join.

Over the years the Forum grew from strength to strength. With increasing numbers of lung cancer nurses joining there became a need for a designated secretariat to support the committee in the day to day running of the Forum. In 2004, Dawn McKinley joined the committee as secretariat and continued in this role until her BTOG workload became too much for her to support both groups. Red Hot Irons took over the secretariat responsibilities in 2014.

Over the years the NLCFN has become recognised as an influential voice of Lung Cancer and Mesothelioma management and the committee members represent the Forum

on a wide variety of national and international groups (see opposite).

Along with other healthcare professionals, charities and interested parties these strategic groups shape, improve and develop lung cancer and mesothelioma care.

Chairs of the committee

Years	Chair/s
1999 - 2000	Darinda Palmer (Claxton), Claire Henry - co chairs
2001 - 2002	John McPhelim, Andrew Wilson - co chairs
2003	Andrew Wilson
2004 - 2005	Tessa Fitzpatrick
2006 - 2008	Maria Guerin
2009 - 2010	Liz Darlison
2011 - 2013	John White
2014 - 2016	Diana Borthwick

Organisations on which the NLCFN is represented

- British Thoracic Oncology Group
- British Thoracic Society (BTS)
- BTS Lung Cancer/Mesothelioma Advisory Group
- Cancer Nursing Partnership
- Global Lung Cancer Coalition
- International Association for the Study of Lung Cancer (IASLC)
- IASLC Allied Nursing and HCP Society
- International Thoracic Oncology Nursing Forum
- Lung Cancer Europe
- Macmillan ERG
- Mesothelioma UK
- National Cancer Registration and Analysis Service
- National Institute for Health and Care Excellence
- National Lung cancer Audit
- NHS England CRG
- National Optimum Lung Cancer Pathways (NOLCP)
- Roy Castle Lung Cancer Foundation
- Scottish Lung Cancer Nurse Specialist Forum
- United Kingdom Lung Cancer Coalition
- United Kingdom Oncology Nursing Service
- Welsh Lung Cancer Nurses Forum

THE ANNUAL CONFERENCE

In 1999 the first annual conference took place in Liverpool. The conference had six speakers, one sponsor and a total of 40 nurses attended. This meeting was primarily a developmental meeting where today's NLCFN was born.

The annual conference has grown year on year through learning, developments in lung cancer and feedback from the delegates (see figure 1).

The committee starts planning the programme in January. They are guided by the feedback received from the previous year's conference, both positive and negative; to make sure the conference is packed with educational, current and interesting topics. The committee approaches key opinion leaders and experts as speakers.

Great care is taken to select a venue which is easily accessible, can accommodate the delegates and plenary programme and exhibition and meets the requirements of corporate governance for sponsors and exhibitors.

Figure 1: Recorded Conference attendance

Year	Speakers	Sponsors	LCNS	Year	Speakers	Sponsors	LCNS
1999	6	1	40	2010	10	60	120
2004	6	20	119	2011	16	60	113
2005	6	22	109	2012	14	67	94
2006	9	38	120	2013	14	60	124
2007	10	39	120	2014	28	61	138
2008	6	43	115	2015	26	94	138
2009	14	55	109	Data unavailable for 2000 - 2003			

Figure 2: National Lung Cancer Forum for Nurses Conference Locations



THE NLCFN ANNUAL AWARD

It was following one of the early conferences that the family of John Lloyd, a patient who was sadly diagnosed and subsequently died of lung cancer, fund raised to provide the first annual award. His grateful family wanted to give back something to the lung cancer nurses who supported them throughout their experience. They continued to fund raise till 2007 when the Forum took over the funding of the award and the name was changed to the NLCFN Annual award.

THE GOOD PRACTICE GUIDE

In the first six years that the Forum was running it became evident that lung cancer nursing was becoming more established. The nurses were developing services and projects that promoted patient care. The Forum, as part of their ethos to share good practice, produced the first Good Practice Guide. Two further Good Practice Guides have been published in 2009 and the latest guide in 2014.

Integrated Lung Cancer Nursing: A Good Practice Guide (2004)

Leading the Way to an Ideal Lung Cancer Service (2009)

Excellence and Innovation in Specialist Lung Cancer Nursing Services (2014)

ANNUAL WORKSHOP WITH LILLY ONCOLOGY

In 2004 Lilly Oncology approached the Forum committee and suggested developing a Workshop for Lung Cancer nurses to develop a national project to further improve patient care. Initially referred to as the 'Lilly Workshop' and with a name change in 2011 the success of this NLCFN Annual Workshop speaks for itself.

The NLCFN Annual Workshop gives lung cancer nurses the opportunity to lead on a national project and present this at the Annual Conference.

During the early years the Workshop attendees were split into two groups to produce two smaller projects. Since 2008 however bigger projects were undertaken and in 2013 saw the first Workshop members' efforts rewarded at the World Conference on Lung Cancer in Australia when the 'Guidance for the Supportive and Palliative Care of Lung Cancer and Mesothelioma Patients and their Carers' was accepted as a Poster presentation.

Annual Workshops to date:

Year	Project Title/s
2004	1. Fail safe Chest X-Ray system: Patient Satisfaction Survey 2. Lung Tracker Job Description
2005	1. Template business case for securing the LCNS role 2. Telephone audit tool
2006	1. Nurse Led Follow Up Guidelines 2. Post operative patient survey
2007	1. Quality indicators; Prevention of hospital admissions audit 2. LCNS core Job Description
2008	A Good Practice Guide on the Prevention of Unplanned Hospital Admissions
2009	Guideline for Lung Cancer Nurse Specialist's to Communicate Key MDT Decisions to Patients
2010	Palliative Radiotherapy guideline & Holistic Needs Assessment Tool Solitary Pulmonary Nodule Guideline
2011 & 2012	Guidance for the Supportive and Palliative Care of Lung Cancer and Mesothelioma Patients and their Carers
2013	Understanding and Reducing Admissions to A&E; The Role of the Lung Cancer Nurse
2014	Improving Survivorship through pre-habilitation at the start of the journey
2015	A Framework to support the Lung Cancer Nurse Specialist in the development and evaluation of nurse-led clinics
2016	Can the early intervention of the Lung Cancer CNS improve the patient experience, pathway, and outcomes for those admitted via the emergency route on first presentation?

RESEARCH INTEREST GROUP

This was developed in 2009. The recognition that audit and research are fundamental in developing lung cancer services resulted in the development of the NLCFN Research Interest Group (RIG). In 2011 the NLCFN RIG introduced a small grants scheme which was launched to support lung cancer nurses to undertake research projects. The Research Interest Group is led by Professor Angela Tod from Sheffield Hallam University.

THORACIC SURGERY GROUP

In 2009 a further sub group of the NLCFN was developed to support those nurses who work in the surgical field of lung cancer. To date, the thoracic surgery group (TSG) has produced essential documents to improve the care of patients undergoing thoracic surgery including:

- Guideline to prepare and support patients undergoing lung resection
- Guideline for telephone follow up for patients undergoing thoracic surgery
- Patient information for enhanced recovery

More recently, the project work from the RIG and TSG groups have been put forward as abstracts at the British Thoracic Oncology Group and poster presentations at the World Conference on Lung Cancer. The groups have been instrumental in developing services, audit and research within lung cancer nursing and made United Kingdom Lung Cancer Nurses gain global recognition.

THE NEWSLETTER

The newsletter is produced 3 times a year. The editor is one of the committee members and NLCFN members are encouraged to write news items on new developments, educational items, feedback from attendance at national and international conferences or general lung CNS new items. The newsletter has grown from strength to strength and is sent out via email to all members.

THE WEBSITE

The website was initially managed by a committee member. It has educational materials and information and is an arena for discussions. The general public can access the website's educational and information pages but NLCFN members have access to the other areas which include details on conferences, member information and other educational materials. It is currently managed by Red Hot Irons as part of their operations team role.



THE TRUSTEES AND BECOMING A CHARITY

The organisation became a Charitable Incorporated Organisation (CIO) on 19 January 2015 giving the organisation more protection. The trustees meet twice per year and occasionally by email/teleconference. The role of the trustees is that of the governance of the organisation. The trustees of the charity are:



Lorraine Creech (Chair)



Alison Leary



John White



Diana Borthwick



Dr Michael Peake

The National Lung Cancer Forum for Nurses is a charitable
incorporated organisation - charity number 1160011
VAT Registration number: 237 6753 78
Correspondence Address: Unit 2 Warwick House, Fairview Industrial Estate,
Kingsbury Road, Curdworth, Warwickshire, B76 9EE
Telephone: 01675 477607 Email: info@nlfcn.net
Web: www.nlfcn.org.uk Fax: 01361 331811