

European Initiative for Quality Management in Lung Cancer Taskforce

Lay report

Introduction

This taskforce was created in September 2010 by a group of interested lung cancer specialists from around Europe, whose aim was to try and improve the quality of care that people with lung cancer get.

Lung cancer is one of the commonest cancers and one of the most lethal cancers throughout Europe and the world despite improvements in care. It is a very serious condition and more than 85% of patients die within 5 years. There is a clear relationship between smoking and lung cancer and interestingly the countries with the highest levels of lung cancer at the moment (Hungary, Poland and Serbia) also have the highest levels of smoking. The country with the lowest level of lung cancer is Sweden and Sweden has the lowest incidence of smoking.

Previous work has suggested that there is variation in treatment and in survival throughout Europe, and it is for this reason that the European Respiratory Society has developed this taskforce.

The main objectives of the project were to gather information on aspects of lung cancer care throughout Europe. There were 4 separate projects undertaken to investigate this further.

1. The first project looked at previous research and publications on quality management in lung cancer.
2. The second project was a survey on a country by country basis to look at the systems of care in individual countries within Europe.
3. The third project was an exercise evaluating lung cancer guidelines in Europe, with the aim of developing certain minimum standards of care.
4. The fourth project was to see how easy and feasible it would be to collect information on lung cancer patients on a day to day basis from the different European countries.

The ultimate aim of all this work will be to have a group of interested doctors across Europe to enable quality management in lung cancer along with definitions of minimum standards of care.

The project also looked at which societies and charities were involved in lung cancer care because these professional and public organisations can influence the quality of care for patients by setting standards as well as promoting good practice and lobbying governments. A total of 18 professional organisations are dedicated entirely to lung cancer and there are also larger organisations involved in the care of lung cancer patients in Europe. It has been realised that there are only 2 European nurse societies and few countries have specific lung cancer specialist nurse societies.

1. Literature Review of Quality Management in Lung Cancer

This literature review was set up to see if there was an evidence base upon which quality management initiatives could be based. In fact the review of the literature revealed that there was no strong evidence available for quality management in lung cancer. A few studies did highlight the benefits of specialist teams of Physicians, Surgeons and Cancer Specialists working together to improve outcomes.

2. Surveys of national and local Lung Cancer throughout Europe

The taskforce was able to identify national representatives from 37 countries in Europe. They were all sent a questionnaire and asked to describe features of the health system with special attention to lung cancer care. The majority of the questionnaires were completed. It turns out that most countries fund their healthcare system through some kind of National Health Service based on income tax contributions but the majority of European countries also have a sector of the health service which is privately funded.

In terms of access to healthcare in the vast majority of countries the normal route for a suspected lung cancer patient to see a specialist is to be referred by their general practitioner/primary care doctor to a hospital specialist, usually a chest doctor. In addition, in every European country patients can go to hospital as an emergency themselves. In terms of providing treatment a range of different specialists

offer chemotherapy for lung cancer. In some countries this is done by cancer doctors called oncologists but in a third of countries chemotherapy is provided by chest doctors. In terms of surgery to remove cancer most countries have specialist lung cancer chest surgeons, but in addition surgeons who operate on heart and lungs do lung cancer surgery in some countries and in a few countries non specialist general surgeons operate.

The survey of local lung cancer care was completed on-line by 350 doctors in 38 countries. There were variations seen in different countries in terms of making a tissue diagnosis of lung cancer by obtaining biopsies. In addition, access to chest surgery varied and in 16 countries patients had to travel over 100km to see a chest surgeon specialist. There was a variation in the use of surgery for lung cancer in different countries, with some reporting a rate as low as 10% but in others it was said to be much higher.

There is a move in many European countries now to develop what is called multi-disciplinary teams. These are groups of specialists including cancer doctors, chest doctors, x-ray doctors, chest surgeons and specialist nurses who work together to try and decide on the best treatment/care for individual patients. The frequency and access to such multi-disciplinary teams of specialists varied across Europe.

3. Review of European Lung Cancer Guidelines

A number of guidelines were identified and reviewed. A total of 56 were assessed. Not all countries had guidelines. Furthermore the quality of guidelines varied and some were very general and some covered only very specific areas. It seems that guidelines produced in the last few years which had input from a government organisation or scientific society, were better.

4. European Lung Cancer Audit (EuLuCA)

The European Lung Cancer Audit was set up to see how feasible it might be to collect information on lung cancer patients from various countries throughout Europe live. The sort of things that we tried to collect were the number of patients, the sex and age of patients, how fit they were and whether the extent and spread of their lung cancer had been accurately recorded. This was done in 23 countries in the month of May 2012 and was only done in patients who had a proven diagnosis of lung cancer following a tissue biopsy. The results of this bit of the project were successful and this showed that it is relatively easy to gather information on a large number of lung cancer patients in different countries in Europe. Established lung cancer data collection programmes in another five countries also shared information on patients with lung cancer.

Summary

This project is hoping to begin a process for improving the quality of care for lung cancer patients throughout Europe. The 4 projects described above were all successfully completed and 37 countries contributed to the national survey and 350 individual specialists from 38 countries contributed to the local survey. The local survey highlights there is still considerable variation in access to care as well as to lung cancer investigations and treatment offered.

The results of this preliminary project suggest it will be feasible and possible to collect data on patients with lung cancer across Europe. By collecting this information from patients across Europe and identifying minimum standards of care the project hopes to improve the quality of care for all patients with lung cancer by driving up standards and harmonising care across Europe