

# HQIP Case Study:

## PPI in national clinical audit – Submission to the Richard Driscoll Memorial Award 2018

**This submission demonstrates:**

**Working with patients to communicate to patients**  
**Building and improving from the learning**  
**First step in building capability of patients**

**Date:** Autumn 2018

**NCAPOP:** National Lung Cancer Audit

**Organisation:** Royal College of Physicians

**Website address:**

<https://www.rcplondon.ac.uk/projects/national-lung-cancer-audit>

### Brief background of the project

In 2017 the National Lung Cancer Audit (NLCA), hosted by the Royal College of Physicians (RCP), decided to develop the National Lung Cancer Audit - Key findings for patients and carers, an accessible summary of our annual report.

We wanted to make something that anyone could pick up and use, a booklet that would re-interpret the clinical language and focus of the annual report into something that could be easily followed by patients and carers.

We wanted patients to better understand the lung cancer pathway and the wider context within which they were receiving their treatment.

### Aim

We wanted to increase the value of the audit by using its findings to help patients better inform themselves about the quality of treatment; we hope this would empower them to work with their clinicians to make joined decisions. We also hoped that patients would gain a basis to compare their treatment against what a high quality lung cancer service could provide.

Central to the project was the prominent and maintained involvement of patients to ensure their advice, voice, language and interests were reflected in the final product.

## Planning and delivery

The process began in April 2017 with the first booklet published in early September the same year.

We worked as a joint project team in collaboration with Roy Castle Lung Cancer Foundation (RCLCF), not only for their expertise in producing patient literature but also as the UK's only lung cancer charity they had a unique access to the people we wanted to work with; we ensured patients were at the centre of and were leading on the direction the booklet took. As the information in the patient booklet was going to include data submitted from England and Wales, we worked to ensure there was representation from both regions.

There were two key phases to producing the patient booklet. The first was to engage the RCLCF reader panel and recruit members who expressed an interest in being part of the project. We sent them a hard copy of the latest NLCA annual report together with a questionnaire. The questionnaire was composed with input from both RCLCF and the NLCA staff and was to determine which aspects of the annual report they found the most useful, relevant and accessible. Following analysis we found that the 'key findings' and 'data results for me' were the most important sections.

The NLCA, supported by RCLCF, then drafted an initial short booklet forming the basis for the second phase. This draft booklet was sent to the reader panel members who expressed interest in further involvement, accompanied by a second questionnaire (again produced by NLCA and RCLCF worked collaboratively) which this time focused on the quality of the information provided. As well as the RCLCF reader panel, this questionnaire and booklet were sent to Cancer Research UK (CRUK), UseMyData (an organisation that promotes the sharing and use of patient data) as well as to the NLCA clinical leads.

The results from this stage were used to adapt the draft into the final content for the booklet that became the *National Lung Cancer Audit: Key findings for patients and carers*. Two patient case studies, provided by RCLCF, were included as well as a patient-written foreword.

The RCP editing and design team took the content and undertook editing and design work to produce the initial 24 page A5 booklet. This format has been continued though the second edition was slightly longer as it included information on two further audits that ran in 2017 within the RCP-NLCA programme, an organisational audit and a spotlight audit.

Of particular interest was a questionnaire response we received through CRUK. A patient diagnosed with a different type of cancer (i.e. not lung) saw benefit in patients providing feedback on patient literature focused on a cancer different to their own. The thinking was that patients can become 'experts' in one particular area, leading to increased use of specialist language which may not be widely understood, even by patients with other cancers.

The patient went back to their local cancer network to suggest cross-site checking of literature. This approach is something we will look to include for future editions.

Hard copies of the booklet are available at RCLCF patient information days, and the NLCA team provides additional copies upon request. Online copies are available for download from both the NLCA website and the RCP website. PDF copies were also sent to clinical leads and lung cancer nurse specialists in England and Wales who were also advised hard copies could be requested at any time.

The case studies are chosen to demonstrate as many different stories of treatment as possible for the different readers to identify and relate to. There is a lot of stigma surrounding lung cancer and we intend for the *Key findings* to empower patients so that they feel more confident when discussing or sharing their story, whether with fellow patients or someone else.

## Impact - the patient view

In 2018 the NLCA sought to investigate the impact of the patient booklet, to see how patients were using the booklet. We ran an online survey, which was publicised on social media by the NLCA and RCLCF, requesting patients or carers who had used the booklet to offer their thoughts on its impact.

Participation was low but feedback was positive. Comments included “I would have liked this booklet when I had my treatment” and the booklet was “good for anyone going through cancer”. This gives us the confidence to know that the booklet is something useful for lung cancer patients.

The NLCA and RCLCF plan to team up again in 2019 to run another evaluation to make sure the Key findings are still presented in the most effective way for patients. We want patients to continue to lead on this and for us to produce what works for them.

## Contact Details

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**Project:** *National Lung Cancer Audit Key findings for patients and carers*

**Team involved:** National Lung Cancer Audit, Roy Castle Lung Cancer Foundation