

NLCA Patient & Public Involvement Forum Terms of Reference

Purpose/role

The National Lung Cancer Audit (NLCA) Patient and Public Involvement Forum will act as a consultative group to the NLCA Project Team providing advisory support through ensuring the voice of patients is central to the direction and delivery of the Audit.

Objectives

The NLCA Patient & Public Forum will:

- Represent the views of patients and act as a consultative group to the NLCA Project Team.
- Provide insight from a patient perspective on all aspects including the Audit's aims and questions.
- Support the NLCA team in a review of the NLCA metrics (performance indicators) and explore future measures.
- Input into the interpretation of NLCA results and explore relevant topics/themes.
- Be active participants in the production of audit outputs including
 - the development and review of patient information materials and summaries of the annual reports.
 - co-development and/or co-authorship of scientific papers that explore NLCA results
- Undertake a key advisory role to the Project Team in developing the design and function of the NLCA's website to ensure that patients and the public can easily find relevant results together with appropriate explanatory information.
- Shape the development of the NLCA's quality improvement goals, activities and outputs by ensuring this work is relevant from a patient perspective.

Membership and representation

- Membership is open to all patients diagnosed with lung cancer up to a maximum of 15 members at a time.
- We are looking for patients who have lung cancer, have survived lung cancer or are a friend, family member and/or carer to a lung cancer patient. The diagnosis of lung cancer should be within the last five years.
- The group should include people with a range of diagnosis, treatment and lung cancer types to reflect the profile of people affected in the UK.
- The Forum will also comprise:
 - Clinical and methodological representatives from the NLCA Project Team
 - Representative/s from the Roy Castle Lung Foundation.
- Patients will be recruited from the Roy Castle Lung Foundation Volunteer Hubs and Patient-led Support Groups with personal experience of lung cancer and who:

- are prepared to discuss treatment, side effects and other issues from a patient’s perspective.
- respect different viewpoints and are happy to engage with a diverse group including health professionals, researchers and charity professionals.
- are flexible and available to join virtual meetings with the possibility of face-to-face meetings.
- have internet access and confidence in using IT software including email, word, power point and pdfs.
- Patients will be appointed to the group through expressions of interest indicating relevant skills and experience.
- All members will be provided with an introductory pack with information about the NLCA.
- A member may change their level of involvement or give up their membership at any time.
- We are looking for an initial commitment of one year in the first instance with the likelihood of extending up to 2-3 years.

Chairing arrangements

- The Chair will be a patient elected by group members at the first meeting and revisited each year.
- The Chair will be supported by the NLCA Project Team, who will be responsible for the administration of the Forum.

Governance

- A member of the NLCA Patient and Public Forum will be appointed by group members as a direct representative in the NLCA Clinical Reference Group to provide advice and recommendations from the Forum with support from the NLCA Project Team.

Frequency and operation of meetings

- Meetings will be held twice a year. Meetings will be held via Teams/Zoom with the possibility of face-to-face meetings once a year at the RCS, London. Attendance via Teams/Zoom will also be available for the convenience of members.
- Refreshments will be provided by the RCS in the event of in person meetings.
- Meeting papers will be circulated electronically in advance of the meeting.
- If members are unable to attend the meeting, they are asked to send comments on relevant papers for discussion during the meeting.
- Minutes/action points will be circulated electronically after the meeting.

Method of communication

- Discussions within the NLCA Patient and Public Forum are considered confidential unless otherwise indicated.

- Communication between the NLCA PPI Forum and the Project Team will be by email.
- Electronic documents will be circulated as required for review.
- The NLCA Project Team will explore the potential for online PPI events with the NLCA PPI Forum including webcasts and webinars on the NLCA website.
- The NLCA Project Team will ensure that all documents and presentations are in a lay-friendly format.
- The NLCA PPI Forum will always be given the opportunity to ask the Project Team for clarification on audit methods or clinical issues that are unclear both during the meetings and by email in between.

Expenses

- In the event of attendance at face-to-face meetings of the NLCA PPI Forum, standard class travel will be booked and paid for in advance.

Reviewing the Terms of Reference

- The Terms of Reference will be reviewed by its members at the first meeting of the Forum and as required during the life-time of the project, to ensure the group's purpose and objectives remain current with the needs of the NLCA.