

National Oesophago-Gastric Cancer Audit (NOGCA) Patient & Public Involvement (PPI) Forum Terms of Reference

The National Oesophago-Gastric Cancer Audit (NOGCA) Patient & Public Involvement (PPI) Forum acts as a consultative group to the NOGCA Project Team, ensuring that the voice of people with experience of living with oesophago-gastric cancer is central to the direction and delivery of the Audit.

The NOGCA PPI Forum will:

- Represent the views of people with experience of living with oesophago-gastric cancer and act as a consultative group to the NOGCA Project Team.
- Be active participants in the production of Audit outputs including
 - the development and review of patient information materials and summaries of the annual “state of the nation” reports.
 - co-development and/or co-authorship of scientific papers that explore NOGCA results
- Shape the development of the NOGCA’s quality improvement goals, activities and outputs by ensuring this work is relevant from the patient perspective.

Membership and representation

- Membership is open to any person with experience of living with oesophago-gastric cancer care in England and Wales, up to a maximum of 10 members. This includes people who have oesophago-gastric cancer, have survived oesophago-gastric cancer or are a carer to someone who has had oesophago-gastric cancer. The diagnosis of oesophago-gastric cancer should be within the last five years.
- The group will include people with a range of diagnosis, treatment and oesophago-gastric cancer types to reflect the profile of people affected in England and Wales.
- The PPI Forum will also comprise:
 - Clinical and methodological representation from the NOGCA Project Team
 - Representation from leading patient charities.
- Members will be recruited who:
 - are prepared to discuss treatment, side effects and other issues from a patient or carer 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 occasional face-to-face meetings.
 - have internet access and confidence in using IT software including email and MS Teams.
- Patients will be appointed to the group through expressions of interest indicating relevant skills and experience.
- A member may change their level of involvement or give up their membership at any time.
- Members are requested to commit for one year in the first instance with the likelihood of extending up to 2-3 years.

Chairing arrangements

- The Chair will be a member of the Forum elected by group members at the first meeting and revisited each year.
- The Chair will be supported by the NOGCA Project Team. The Project Team will be responsible for the administration of the Forum if required.

Governance

- A member of the NOGCA PPI Forum will be appointed by group members to represent the Forum in the NOGCA Clinical Reference Group (CRG). The CRG is an advisory group that provides specialist expertise and professional guidance on the direction and activities of the Audit.

Frequency and operation of meetings

- Meetings will be held twice a year. Meetings will be held via Teams with the possibility of face-to-face meetings once a year at the RCS, London. Attendance via Teams will also be available for the convenience of members.
- In the event of attendance at face-to-face meetings of the NOGCA PPI Forum, requests for reimbursement of standard class travel will be reimbursed.
- 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 NOGCA PPI Forum are considered confidential unless otherwise indicated.
- Communication between the NOGCA PPI Forum members and the Project Team will be by email.
- Electronic documents will be circulated as required for review.
- The NOGCA 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.

Reviewing the Terms of Reference

- The Terms of Reference will be reviewed by its members on an annual basis to ensure continued alignment with the needs of the Audit.

Last updated: 07/2024

Next review: 07/2027