

## NPCA Patient & Public Involvement Forum Terms of Reference

### Purpose/role

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

### Objectives

The NPCA Patient & Public Forum:

- Represents the views of patients and act as a consultative group to the NPCA Project Team.
- Provides insight from a patient perspective on all aspects including the Audit's aims and questions.
- Supports the NPCA team in a review of the NPCA metrics (performance indicators) and explore future measures.
- Inputs into the interpretation of NPCA results and explore relevant topics/themes.
- Are active participants in the production of audit outputs including the development and review of patient information materials and summaries of the annual reports.
- Undertake a key advisory role to the Project Team in developing the design and function of the NPCA's website to ensure that patients and the public can easily find relevant results together with appropriate explanatory information.
- Shape the development of the NPCA'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 men diagnosed with prostate cancer up to maximum of 12 members at a time.
- The Forum also comprises:
  - Clinical and methodological representatives from the NPCA Project Team
  - Representative/s from PCUK and Tackle Prostate Cancer.
- Men are recruited from Prostate Cancer UK's Volunteer Hubs and Tackle Prostate Cancer's Patient-led Support Groups with personal experience of prostate 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 able to travel to annual face-to-face meetings.
  - have internet access and confidence in using IT software including email, word, power point and pdfs.

- Men are appointed to the group through expressions of interest and an informal interview.
- All members are provided with an introductory pack with information about the NPCA.
- A member may change their level of involvement or give up their membership at any time.
- The period of membership is for two years in the first instance with an option to continue.

### **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 NPCA Project Team, who will be responsible for the administration of the Forum.

### **Governance**

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

### **Frequency and operation of meetings**

- Face-to-face meetings will be held twice a year at the RCS, London, when possible. The first meeting will take place virtually in April 2020. For face-to-face meetings, attendance via teleconference or skype/zoom will also be available for the convenience of members.
- Refreshments will be provided by the RCS for in person meetings.
- Additional meetings by teleconference will be held on an ad-hoc basis.
- 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 NPCA Patient and Public Forum are considered confidential unless otherwise indicated.
- Communication between the NPCA PPI Forum and the Project Team will be by email.
- Electronic documents will be circulated as required for review.
- The NPCA Project Team will explore the potential for online PPI events with the NPCA PPI Forum including webcasts and webinars on the NPCA website.



- The NPCA Project Team will ensure that all documents and presentations are in a lay-friendly format.
- The NPCA 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 face-to-face meeting and by email in between.

### **Expenses**

- Standard class travel for attending face-to-face meetings of the NPCA PPI Forum will be booked and paid for in advance.
- The NPCA will cover the costs of teleconference or skype calls.
- Business reply envelopes are provided for correspondence by post.

### **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 NPCA.