



## **Patient Reference Group**

### **Terms of reference**

#### **Definition**

The Patient Reference Group is an advisory group responsible for providing independent advice and feedback to help inform the activities of PCRS.

#### **Purpose**

The purpose of the Patient Reference Group is to help:

- Promote a patient centred approach within corporate consciousness' of PCRS and all its activities.
- Offer the patient perspective in discussion, policy and decision making throughout the organisation.
- Help to ensure PCRS is acting ultimately in patients' best interests and providing public benefit.

#### **Composition**

The PRG will be comprised of 6-8 patients, ideally of different genders, ages, and backgrounds with experience of a variety of respiratory problems typically seen in primary care.

The Group will be co-chaired by both a member of the group itself and the CEO of PCRS. The Co-Chairs will together plan and agree the agenda for meetings. With the CEO of PCRS ensuring appropriate links into PCRS strategy and operational activity and the Patient Reference Group Chair being responsible for liaison with other members of the PRG.

The group shall nominate the Patient Reference Group chair from the membership of the group, who shall be appointed for a period of 2 years (renewable for up to 3 terms).

The Chair PCRS Executive (or designated deputies) will attend the group at least once per annum to participate in discussions, provide points of clarification on the activity of the organisation, and offer advice, but shall have no voting rights.

#### **Appointment of members**

Members of the group will be recruited through a mixture of channels, via the PCRS membership and any other relevant organisations. Persons interested in joining the group will be asked to provide a supporting statement explaining why they are interested, which will be reviewed by the Co-Chairs of the group and interviewed by two other PRG members who will make the final recommendation on appointments, with the Executive Committee approving final recommendations.

Members will be appointed for a 3 year term to the group (renewable for up to 3 terms).

All members of the group will be offered relevant training and support where funding allows to help them make an effective contribution to the group.

All members of the Group are expected to abide by the PCRS code of conduct.

#### **Removal of members**

Any member of the PRG may cease to be a member of the PRG if the member:

- Chooses to resign.
- Becomes incapable of attending or contributing to the activities of the Group by reason of illness or injury.
- Is absent without explanation from two consecutive meetings and the PRG resolve that the member's place be vacated.

- Is deemed to have brought the Charity into disrepute and is asked by a majority of the Group or directly at the request of the Executive Committee to resign their membership. The member concerned may appeal to the Executive or the Trustees (in cases where the Executive Committee makes the request). The decision of the Board of Trustees is final.

### **Working practices & process**

Involving PRG in the work of PCRS:

- 1-2 members of the group will be invited to join (as non-voting member) each of the following PCRS committees for an initial term of three years: Education, Service Development, Conference Organising Committees, Policy Forum and PCRS Executive.
- The group will be invited to contribute content such as blogs, podcasts, articles, soundbites/quotes, and interviews where such content is relevant to the activity and priorities of the charity.
- Group members will be invited to contribute their expertise to PCRS research network members who would like lay input into their research proposal but who do not have ready access to patient/public involvement (PPI).
- Members of the group will be invited to attend the PCRS conference and to feedback their observations with respect to how well the sessions succeed in supporting a patient centred approach.
- Members of the group will receive all PCRS membership communications, including e alerts and Primary Care Respiratory Update with an open invitation to feedback their observations from a patient perspective.

### **Meetings and communication**

- The group will meet twice a year via video conference to review progress, comment on current/future plans for the Society and debate key issues. The group may also meet at Annual Conference informally.
- The Co-Chairs of PRG shall develop and agree agendas for meetings of the Group.
- A quorum of the Group shall be three
- Conflicts of interest will be declared at the start of each meeting in line with PCRS conflict of interest policy
- At each meeting a member of the group shall be asked to take brief notes of actions agreed.
- On-going communication with the group and between group members will be via email
- The PRG Co- Chair shall sit on the PCRS Executive and will liaise with other group members to encourage input and invite feedback from the wider group to help inform PCRS Executive Committee Discussions.

### **Expenses**

PCRS are keen to ensure that no member of the PRG is worse off as a result of contributing their time to PCRS. PCRS will therefore reimburse such costs incurred in the course of activity as a member of the PRG. This includes reasonable travel and accommodation costs payable in line with PCRS Expenses policy. In addition, PCRS will offer an honorarium for attendance at face to face PCRS meetings.

### **Revised May 2021**

**Reviewed by PCRS Executive: May 2021**

**Approved by PCRS Trustees: July 2021**

**Date of next review: May 2022**