

**Lay patient and carer reference group**

**Terms of reference (revised September 2017)**

**Definition**

The lay patient and carer reference group is an advisory group responsible for providing independent advice and feedback to PCRS-UK Executive.

**Purpose**

The purpose of the Lay patient and carer reference group is to help;

* Promote a patient centred approach within corporate consciousness’ of PCRS-UK and all its activities
* Help to ensure PCRS-UK is acting ultimately in patients’ best interests and providing public benefit

**Composition**

The Lay patient and carer reference group will be chaired by a PCRS-UK Trustee and 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 Chief Executive and Chair PCRS-UK Executive (or designated deputies) will attend the group but will not participate in the discussion directly except when invited to provide points of clarification.

**Appointment of members**

Members of the group will be recruited through a mixture of Asthma UK and the BLF channels and via the PCRS-UK membership. Persons interested in joining the group will be asked to provide a brief CV and supporting statement explaining why they are interested, which will be reviewed by the Chair of the group who will make the final decision on appointments .

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

All members of the group will be offered training and support (via BLF/Asthma UK) to help them make an effective contribution to the group.

**Working practices & process**

Involving LRG in the work of PCRS-UK

* 1-2 members of the group will be invited to join (as non-voting member) to each of the following PCRS-UK committees1 for an initial term of one year: Education, Service Development, Conference Organising Committees, Policy Forum and PCRS-UK Executive
  + In addition to contributing within the meetings, members of the LRG will be invited to provide written feedback and observations of each committee meeting they attend, back to the LRG and to the Committee with respect to how well the committee is achieving PCRS-UK‘s goal of developing a more patient centred approach
* The group will be invited to contribute an article to each issue of Primary Care Respiratory Update relevant to the theme of that issue; article to be written by PCRS-UK communications consultant based on an interview with relevant LRG member(s)
* Group members will be invited to contribute their expertise to PCRS-UK research networks members who are who are keen/need to get lay input into the 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-UK 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-UK 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**

* An annual face to face meeting of the group will be held, during the PCRS-UK annual conference, to review progress over the last 12 months, comment on current/future plans for the Society and debate key issues
* On-going communication with the group and between group members will be via email
* The LRG representative(s) on PCRS-UK Executive will be expected to take a lead role within the group by:
  + Encouraging active discussion and on-going dialogue within the group relevant to the work of PCRS-UK, supported by the Trustee Chair of the group/PCRS-UK communications consultant
  + Developing and agreeing an agenda for the annual meeting of the group with Trustee chair of the Group.

1  Two meetings of PCRS-UK Executive, Education Committee, Service Development Committee (6 monthly) Conference Organising Committee (both October -December) and one meeting of the policy forum is held each year are held each year, each one a day (10-4) in central London.

**Expenses**

Travel costs will be reimbursed to members attending a PCRS-UK meeting. Car travel costs will be reimbursed at a rate of 45p per mile and rail or air fares will be refunded at standard class upon presentation of a valid receipt. In addition PCRS-UK will offer an honorarium of £200 per full day for attendance at PCRS-UK meetings.

**Date of next review**: September 2018