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**Patient involvement in Primary Care Respiratory Society UK**

**Lay patient and carer reference group**

**Background**

The Primary Care Respiratory Society UK (PCRS-UK) is a registered Charity and the UK-wide professional society supporting primary care to deliver high value patient centred respiratory care.  Our ultimate vision is “***optimal respiratory health for all***” which we seek to achieve through:

* Campaigning to[influence policy](http://www.pcrs-uk.org/influencing-policy)and set standards in respiratory medicine, relevant to primary care nationally and locally: the voice of primary care in respiratory medicine
* Educating primary care health professionals to deliver and influence respiratory care
  + Open access best practice, evidence based clinical guidance and [resources,](http://www.pcrs-uk.org/primary-care-respiratory-resources)produced by primary care respiratory experts for primary care
  + Membership scheme to support the respiratory professional development and empower primary care health professionals to [provide and commission](http://www.pcrs-uk.org/service-improvement)high value, patient-centred care
* Promoting and disseminating real life primary care [research](http://www.pcrs-uk.org/research)in respiratory conditions to support policy and education activities

Our scientific journal, ***[npj: Primary Care Respiratory Medicine](http://www.nature.com/npjpcrm/)***, flagship Annual National Primary Care [Conference](http://www.pcrs-uk.org/pcrs-uk-annual-conference), [Affiliated groups](http://www.pcrs-uk.org/local-groups) and [Quality Award](http://www.pcrs-uk.org/pcrs-uk-quality-award) underpin our research, campaigning and education work.

We are a membership-led organisation, with formal company (or 'voting') membership open to any healthcare professional working in primary care in the UK and ordinary [membership](http://www.pcrs-uk.org/join)  open to anyone interested in primary care respiratory medicine. The [PCRS-UK Executive](http://www.pcrs-uk.org/primary-care-respiratory-society-uk-executive) is responsible for developing and coordinating the activities of the Society and is accountable to the [Board of Trustees](http://www.pcrs-uk.org/primary-care-respiratory-society-uk-trustees).

Further information on PCRS-UK can be at [www.pcrs-uk.org](http://www.pcrs-uk.org)   
The annual report and accounts can be downloaded at:

<https://www.pcrs-uk.org/sites/pcrs-uk.org/files/files/2014_Final_Accounts.pdf>

**Objectives**

PCRS-UK recognises the importance of patient centred care and set up up a lay patient and carer reference group in 2015 in order to;

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

**Definition**

The lay patient and carer reference group is an advisory group responsible for providing independent advice and feedback to PCRS-UK Executive and trustees on how well the Society is performing in relation to the above objectives.

**Composition**

The Lay patient and carer reference group is chaired by Mrs Jane Scullion, a respiratory nurse consultant and a PCRS-UK Trustee. The group is comprised of 6-8 patients from across the respiratory disease and age spectrum seen commonly in primary care, including for example;

* Young person with asthma
* Parent of a young child with asthma
* Working/middle aged adult with asthma
* Working age adult with early stage COPD
* Adult with more severe/advanced COPD or other chronic respiratory disease
* Carer of person with severe disabling respiratory disease

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 are recruited through a mixture of Asthma UK and the BLF channels and via the PCRS-UK membership. Persons interested in joining the group are 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**

* An annual meeting of the group is held, during the PCRS-UK annual conference, to feedback on PCRS-UK activities over the last 12 months and to comment on current / future plans for the Society. Members of the group are invited to attend sessions during day 1 of the PCRS-UK conference
* Structured feedback is sought via email from the group midway through the year between meetings on what they observe the Society to be doing well and areas for improvement with respect to patient centred care and operating ultimately in the best interests of patients
* A twice yearly report from the group should be provided to the PCRS-UK Executive and Trustees
* Members of the group are set up as PCRS-UK members such that they receive PCRS-UK membership correspondence and Primary Care Respiratory Update (members’ magazine). In addition, members of the group are provided with information on the work of the Charity as follows:
  + PCRS-UK Executive minutes (bi annual)
  + Annual business plan
  + Trustees annual report and statement of financial / accounts
* 1-2 members of the group are asked to contribute to the planning of PCRS-UK annual Conference 1
* 1-2 members of the group are invited on a rotating basis to attend each PCRS-UK Executive meeting 2

1 Contribution will be viaattendance at the main planning meetings of the Conference Organising Committee (1 full day meeting with possibly a second meeting) and thereafter via email or phone.

2 Two meetings of PCRS-UK Executive are held each year, each one a day (10am-4pm) 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 £150 per full day for attendance at PCRS-UK meetings.



Official Journal of the PCRS-UK <http://www.nature.com/npjpcrm/>

The Primary Care Respiratory Society, is a registered charity; (Charity No: 1098117) and a company limited by guarantee registered in England (Company No: 4298947). VAT Registration Number: 866 1543 09. Registered offices: PCRS-UK, Unit 2 Warwick House,

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