



GUIDANCE ON SETTING UP A NATIONAL PRIMARY CARE RESPIRATORY GROUP

CHAPTER ONE

Introduction

As well as being a global community of interest and practice, the IPCRG is an organisation of organisations. That is, its members, who have voting rights, are national primary care organisations. This guide describes how such organisations can be formed, and how they get elected to be members of the IPCRG.

What is the IPCRG?

The International Primary Care Respiratory Group (IPCRG) is a charity registered in Scotland working internationally (SC No: 035056) and a company limited by guarantee (Company number 256268) managed by a multi-national board of directors. It is the primary care representative on WHO-Global Alliance against Chronic Respiratory Diseases (GARD) Planning Executive, the Respiratory Special Interest Group of WONCA Europe and an Organisation in Collaborative Relations with WONCA Global, a member of the European COPD Coalition and a supporter of the NCD Alliance. The IPCRG has a special interest in long term respiratory conditions such as chronic obstructive pulmonary disease (COPD), asthma and allergic rhinitis, other common primary care respiratory problems such as respiratory infection, as well as tobacco dependence. It has a philanthropic mission to share and spread evidence for the public good.

We currently have 23 full members, for example, the Primary Care Respiratory Society-UK, CAHAG in the Netherlands, the Chest Research Foundation India, IPCRG-Pakistan. Through our members we reach at least 125,000 primary care professionals worldwide. We also have a similar number of associate members countries. Our associate membership scheme includes associate corporate members, associate invited organisations including the European Federation of Allergy and Airways Diseases Patients' Association (EFA), World Allergy Organisation and Education for Health as well as [invited specialists](#) including Stephen Holgate, Jean Bousquet, and Alvaro Cruz. We have close working relationships with the European Respiratory Society (ERS), for whom we wrote the primary care chapter of the [White Book 2013](#), and feed the membership of the Primary Care Group within ERS. We have also supported the recent establishment of a primary care group within the European Academy of Allergology and Clinical Immunology (EAACI) and its leadership is also drawn from our members.

What is the IPCRG membership policy?

The IPCRG constitution ("Memorandum and Articles") allows there to be one member per country, irrespective of the country size. The election process is described in the IPCRG's membership policy (see Appendix), the summary of which is:

The IPCRG will have low barriers to entry to encourage the formation of new member groups and stimulate their growth and development based on a written project about existing/future direction of the group.

What do IPCRG members do?

In their own country

- Create a forum (online and/or physical meetings) for primary care colleagues to learn, share experience and improve their care of people with chronic respiratory disease
- Raise the standard of respiratory care throughout the country through influencing guidelines, teaching and mentoring
- Promote to policy-makers the role of primary care in the detection and management of people with chronic respiratory disease through collection of routine data, analysis and research

With IPCRG: Responsibilities

- Nominate a representative to attend the Annual General Meeting that elects the IPCRG President and Treasurer
- Select the host country for the next biennial conference
- Contribute ideas, data, comments and challenge to the IPCRG's research, education and advocacy programmes as part of the IPCRG Senate

Full details of the organisational structure [here](#)

With IPCRG: Rights

- Be eligible for roles on the decision-making bodies of the IPCRG including the Research sub-committee, Education sub-committee, and the Board of Directors that is responsible for policy, strategy and risk management.
- Be eligible for benefits such as bursaries and participate in IPCRG-funded calls such as E-Faculty (to improve research capability), E-Quality (education programmes to improve clinical behaviours), IPCRG Research Fellow.
- Participate in IPCRG research such as UNLOCK if the eligibility criteria are met
- Have access to any of the private web forum open to members
- Pages on our web-platform with editing rights

For information about the current (2014) opportunities see pages 4-6.

What are the criteria for new members?

Criteria

Full ("Ordinary" in legal terms) members (country groups with a primary care respiratory interest) will be recommended by the Board for adoption by the members at the annual general meeting if they are judged sufficiently robust and can provide evidence of

1. Written rules including inclusive membership rules appropriate for a primary care group with a respiratory interest in that country
2. Geographical spread: representation from more than one university/region
3. Independence from undue influence (eg pharmaceutical industry, politics, secondary care, commercial enterprise)
4. A non-personal bank account so that funds raised for primary care respiratory purposes are safeguarded for those purposes
5. Elected officers with a limit on the terms of office

6. An up-to-date list of members that the group represents and a way of contacting them
7. A process for seeking and representing members' views
8. Written plan about existing/future direction and materials (membership, activities, resources, research, presence and influence)

Associate members

The Memorandum and Articles also allows for individuals in a country, who have not yet formed an association, to join the IPCRG as associate members. It is the IPCRG's aim to convert associate members into full members, by supporting them to form a robust representative organisation. Therefore until the group can meet all eight of these criteria they will remain as an associate member, and continue to have the support and help of the IPCRG to work towards full membership.

Election

The IPCRG Board makes a recommendation to the members who may pass a Special Resolution (75% of the votes needed to be passed) at their annual general meeting to elect an organisation to full voting membership.

More than one group in a country

Where there is more than one group in a country that wants to be the IPCRG member, the IPCRG will enable all groups to be associate members. To become an Ordinary Member, the responsibility lies with the groups to find a representative solution because IPCRG permits only one member and one vote per country. Solutions might include a number of groups forming a federation, coalition, or network, with shared leadership, with a Chair/President role that rotates after a fixed period between the different groups.

Whatever solution is proposed, it must always be studied by the Board and ratified by the members at an Annual General Meeting.

If a local solution cannot be found, then the IPCRG Board may decide which group it will recommend to the members be elected based on the evidence it has of the

1. Size and scope of the groups
2. Their connection to primary care and their ability to influence primary care
3. Level of recent activity
4. Evidence of an ethos that fits with the inclusiveness, networking approach of the IPCRG
5. Their perceived independence from undue influence (eg pharmaceutical industry, politics, secondary care, commercial enterprise)

These notes and questions are designed to help you set up as an organisation and member of the IPCRG. They help you decide what organisation is right for you and your current stage of development. The IPCRG members have many different forms of organisation, and as long as the IPCRG directors judge these to be robust and representative of primary care in that country, it will welcome them to membership.



We include the basic questions necessary to decide how to begin. There is a separate document that deals with more complex questions that may be necessary to ask only after several years of operation. It is your choice how you use them.

Current opportunities for engaging in IPCRG research and education

[See Why Join](#)

CHAPTER TWO IPCRG'S STANDARD FOR FULL VOTING MEMBERSHIP

This checklist may help you judge how robust your organisation is:

- | |
|---|
| <ol style="list-style-type: none">1. Do you know who your members are and can you provide contact points for them?2. Do you have membership rules and are these appropriate for a primary care respiratory organisation?3. Do you have a policy and process for safeguarding funds that you may receive?4. Do you know who is in charge (be that one person or a committee)?5. Is there an agreement about representation – how is/are the representative(s) selected and deselected and how do they canvass members' opinions? |
|---|

If you can answer “yes” to all these questions and provide some evidence of them, you are probably ready to become a full member.

Who?

Who is your organisation for?

We recommend you are as inclusive as possible, as long as the experience and competence of members is the primary care management of respiratory disease. This will depend on your health system and might include family physicians, physiotherapists, nurses, health workers, paediatricians and pulmonologists working in the community. It might also include primary care academics. Secondary care practitioners might also be invited as full or honorary members.

Consider what relationship you want to have with:

Public and Patients
Government/policy makers

You may also want to consider associate membership for:

Patient groups
Retired practitioners
Industry
Secondary care
Others

You will need to keep membership details in a database such as xls or a customised membership database. Data you might wish to include:

Database

- Name
- Contact details including email and mobile phone, as you may want to use group emails or text messages to contact your members. The use of emails to contact members is very cost effective and makes the running of the organisation much easier. It is also useful to keep address details so that in the fullness of time when your membership numbers have increased you may opt to undertake regional projects to meet the local needs of your membership
- Profession

Your database should be structured, robust, searchable and in a form that allows you to produce reports easily. It should also be flexible to allow you to add additional fields as your organisation and needs grow.

You should also investigate your country's data protection and/or other legal obligations and requirements and decide whether you want, if you can, have the power to share the database with others.

Consider:

Will you have the power to share the names of members with other members?

If you have a mailing list, is it permitted to pass this to a third party and do you want to? The mailing list is a **very** valuable asset for the pharmaceutical industry, for example, and therefore you might not want to release this information. If you do release the list to others, do so for a defined purpose and time. Alternatively, if you want a publisher to issue your in-house journal/newsletter, you will need to have the power to hand over the mailing list to the publisher. This will probably require consent, demonstrated by a signature of each member. Therefore you may also require some paper record storage.

It may be useful in the long term if you include a statement in the membership registration information which explains how you plan to use the data collected on your membership and allowing members to opt in/out of options on the use of their data. This may save you time in receiving approval from them at a later date.

What?

What is the organisation for?

The answer will help determine the most suitable form of organisation. Is it for:

Networking? The latest research on knowledge management suggests that one of the important ways specialists like you learn and improve your decision-making processes is through social interaction and case-studies and stories that develop new neural pathways.



Clubs and societies (un-associated organisations) are often the form of organisation used if this is the primary purpose.

Guidelines? A number of our members came together first as a working party to produce respiratory guidelines for primary care. The next stage might be to set yourselves up as a separate and permanent group.

Education? To improve the competence of all those working in primary care or with a special interest like you? Clubs and societies can do this, or you might start off as a sub-group of your College of General Practitioners. The IPCRG is an Organisation in Collaborative Relations with WONCA global and the Respiratory Special Interest Group (SIG) of Wonca Europe. It may be able to help you build this relationship if you wish.

Research? Research organisations will need more formal structures if they are to receive, manage and account for grants, hold data and meet current research governance standards. These might be provided through a link with a university, but links with one university might dissuade people affiliated to another university from joining.

If you want to **improve your opportunities for income**, consider whether certain forms of organisation improve the range of opportunities. Can you register as a non-governmental organisation (NGO)? For example, in England and Scotland, “charities” are exempt from certain taxes. The eligibility criteria for charities include activities for the public benefit, such as research.

What respiratory interests will you represent?

The IPCRG’s remit includes

- Asthma
- Allergic Rhinitis and rhinosinusitis
- Tobacco dependence
- Chronic Obstructive Pulmonary Disease
- Obstructive sleep apnoea and
- Infectious diseases including respiratory tract infections and TB

This enables us to be attractive to the widest circle of members. You will need to choose what to include. You can always start with a few and broaden out later.

What will you be called?

The simplest name to consider would be [Country] Primary Care Respiratory Group or IPCRG- [name of country]. You should also have a **logo** and protect its use since you need to control how it is used otherwise it might be used by others to endorse certain products or events or policies.

Your name and logo are important and will be the cornerstone of your brand image. You must spend appropriate time and resources in developing the name and logo for the organisation. Avoid using images or type-faces which are too similar to any particular



pharmaceutical company. You can now use crowd sourcing to design logos at low cost: for example www.designcontest.com/ or 99designs.co.uk or www.logomyway.com/

Where?

Do you need a physical base? An office? A records storage facility? Or can you operate virtually? The IPCRG and most of its members conduct their business mainly electronically and telephonically. They would recommend some face-to-face meetings, but they are costly in terms of travel and accommodation. Consider the use of phone conferences using Skype, email and webcasts such as Webex.

The IPCRG has a web platform that you can use including password-protected areas. We can create some pages for you and offer you editing rights. You can store documents here and make them available to invited people.

Often the Colleges of General practice may offer you some office space and computer facilities, many of the member organisations work closely with the colleges.

If you intend to run educational meetings, you will probably know where best to run these to attract most delegates but we can also offer guidance.

How?

How you will make **decisions**? (“Executive” means those with responsibility for getting things done, and so is often the name given to a small group within the organisation).

To begin with, you may appoint an Executive Committee. In the first year, this may not be an elected committee, as you may be the only members! However, as numbers grow, you will need to organise a voting process. The simplest way to do this is to have an election for the Committee periodically.

If you are a charity (not for profit organisation), then you will need to have a separate Board of Trustees.

You might also want a category of non-voting members.

How will you get things done?

The pace of your work will be dependent on 2 things:

If you want the members to deliver the education, research and publications, then the pace will be determined by how fast they can deliver, in addition to practising as primary care workers. Most organisations rely on their members doing work voluntarily, in return for their personal development and gaining a new community or network for discussion, education, research in their area of special interest.

If you want to commission work, it will be dependent on how much income you have to commission work. You might want to consider funding:

- Management
- Administration
- Writing
- Education
- Policy advice and lobbying
- Fundraising
- Press and public relations

In addition to your local contacts and grant-giving organisations, the IPCRG office may be able to put you in contact with local companies such as the pharmaceutical industry that may be interested in helping you hold an education meeting where you might recruit members; or help you distribute a newsletter.

How will you be funded?

There are a number of options to gain **income**:

Subscriptions: personal or group membership, fees for meetings

Sales: pamphlets, books, articles

Sponsorship: for meetings, research, core funding.

Longer-term, you will have more credibility with policy makers, the public and your peers if you have more than one source of income; for example, multi-funding by the pharmaceutical industry, a mix of donations and sponsorship and grants.

Be careful when dealing with single sponsors, and beware of single sponsors getting too close; it can damage your reputation as a credible independent voice

Source of income	Meetings	Publications	Research	Membership
Subscription	√	√		√
Sales		√		√
Sponsorship	√	√	√	
Donations	√		√	
Advertising	√	√		

The IPCRG primarily uses a subscription business model to gain income. It has a category of associate membership with different subscription levels for different members. Individuals currently pay £0, pharmaceutical companies and device companies join as associate corporate members and each pay a subscription fee. You will find our current associate corporate members and the relevant paperwork [here](#)

In addition, the IPCRG accepts donations, sponsorship of particular projects and may consider web-advertising in the future.

Expenditure

You need to decide who controls this, and to keep records of both income and expenditure and report once a year to your members.

You will also need to ensure you meet the legal and regulatory requirements of your country in terms of financial reporting.

If you are a registered charity you will also have to comply with the instructions for financial reporting that the governing charity body requires in your country.

CHAPTER THREE

For organisations that have a robust set-up

Communication

The basis of your success will be how well you deliver messages, and how well you receive them.

What **methods** of communication will you use?

- Dialogue
- Letter
- Email
- Newsletter
- Journal
- Adverts
- Web site
- Social media: Twitter, Facebook

What will you communicate?

- Your chosen vision
- Your aims and objectives
- Your business plan
- News
- Research findings
- Responses to national consultations

Consider who needs to own these decisions, who needs to buy into them, who just needs to be aware of them?

Leadership

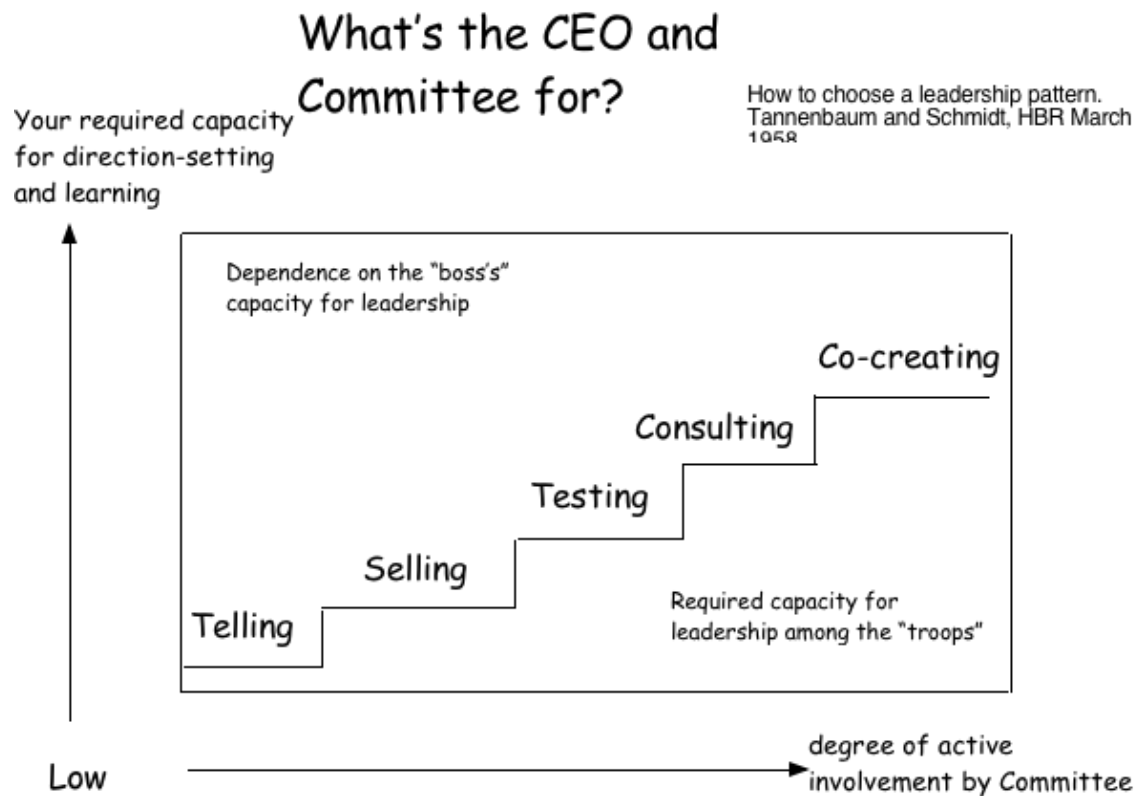
To begin with, there is likely to be one individual or a small team of people who have the interest and volunteer their time to set up the organisation. They will naturally be the leaders.

Over time, you may want to consider:

- Who leads the organisation?

The model of leadership you choose will depend on 2 dimensions: your group's readiness and capacity to take responsibility, and how much you want to depend on a leader [How to choose a leadership pattern. Tannenbaum and Schmidt. HBR March 1958]. For example, do you want an Executive Officer, or a Chairman, or will you have a Committee that leads together?

Tannenbaum and Schmidt's Situational Leadership Model.



Case study

The model chosen by the Primary Care Respiratory Society-UK was co-creation, a joint venture between the Chief Executive and the Committee. Co-creation requires clear personal visions that are aligned; a sense of common purpose and a mutual understanding of the current realities and, most importantly, action to move forward together [Senge P. The Fifth Discipline Fieldbook. 2000.]

What are your values?

In Principle Centred Leadership by Stephen Covey, 2000, he argues that what binds an organisation together and makes for successful leadership is not wisdom, power, guidance, or security, but principles, which link all these other four qualities together. So, what are your values and principles? For example, you will be approached by organisations wanting your badge of approval. Are you willing to endorse their work if you have not been an active partner in it?

Developing a business plan

If you want to expand, and attract sponsorship, you will need a business plan. The basis of this should be good ideas. Good ideas that are presented well have a good chance of getting some attention. Using the Kaplan Balanced Scorecard approach, there are 4 pillars to achieving a successful organisation:

Increase member value

Expand, deepen or redefine relationships with members. This requires you to know who your members (customers) are.

Build the franchise

If you started out as an organisation for general practitioners, do you now want to be an organisation for primary care? If you started out producing guidelines, do you want to develop new services such as education or research or publications? If you started out in one region of your country, do you want to expand geographically?

Operational excellence

Are you running your organisation as efficiently as possible? Are you keeping your costs down, and expanding your opportunities for raising funds? How good are your communications? Are you gaining members each year? Your business plan will also need to include appropriate timelines. You must remember that many of your members will be undertaking work for the organisation as a volunteer alongside their everyday job and, unless you have commissioned the work, your timelines must be realistic and reflect the fact that the work may be being undertaken on a part-time basis. You need to be sure that any sponsors/funders are aware of the proposed timelines.

Good corporate citizen

Your sustained existence depends on other stakeholders believing your organisation is worthwhile and worth supporting and endorsing. Who are the stakeholders? What are you doing to manage relations with them?

So, a business plan might include plans for

1. Increasing membership
2. Developing activities in education, research and publications
3. Ensuring your organisation works efficiently and manages risk successfully
4. Define your external stakeholders and develop a plan for building relationships with them

The business plan needs to have a **budget** that describes the plan in terms of what it will cost to deliver it, and what income might be gained.

Control of budget

You will need to decide:

- Who approves the budget?
- Who is responsible for managing the budget
- How are payments authorised
- How are payments made

It is important that you regularly review the outcome of your work and you must seek to identify measurable outcomes at the outset of any new work so that these can be reviewed and any issues identified and addressed in future work. It is often useful to form sub-committees and co-opt those who have been commissioned to undertake the work together with sponsors/funders for individual projects. In this way you can ensure that the objectives of all stakeholders are taken into account and any issues addressed before they become problems and inhibit progress.

Legal issues and litigation

If members wish to limit their liability, for example, if the organisation incurred a financial loss running an event, and individual members did not want to be responsible for paying for that loss, then consider certain legal organisations such as certain forms of incorporation that can limit liability. The IPCRG is a charity and also a company limited by guarantee.

The IPCRG, Primary Care Respiratory Society-UK and other members have policies on the following that we can share with you when you reach these points:

- intellectual property
- research governance
- sponsorship and endorsement
- risk management
- constitutions



- contracts
- payment authorisation

We hope these questions help you decide on the shape of your organisation.

If you require further help, please contact the IPCRG Secretariat.

Siân Williams
Executive Officer
Revised May 2014

<http://www.theipcrq.org>



APPENDIX

IPCRG Membership policy: Ordinary and associate members (countries)

Purpose

To support implementation of the IPCRG's strategic objective:

Sustain and grow relevant research and educational and programmes by building a strong framework of members that engage clinicians and researchers in the delivery of high quality respiratory care in the community

Policy

The IPCRG will have low barriers to entry to encourage the formation of new member groups and stimulate their growth and development based on a written project about existing/future direction of the group. This project will be reviewed by the IPCRG and the group itself every two years.

Entry of new members

Criteria

Full ("Ordinary" in legal terms) members (country groups with a primary care respiratory interest) will be recommended by the Board for adoption by the members at the annual general meeting if they are judged sufficiently robust and can provide evidence of

1. Written rules including inclusive membership rules appropriate for a primary care group with a respiratory interest in that country
2. Geographical spread: representation from more than one university/region
3. Independence from undue influence (eg pharmaceutical industry, politics, secondary care, commercial enterprise)
4. A non-personal bank account so that funds raised for primary care respiratory purposes are safeguarded for those purposes
5. Elected officers with a limit on the terms of office
6. An up-to-date list of members that the group represents and a way of contacting them
7. A process for seeking and representing members' views
8. Written plan about existing/future direction and materials (membership, activities, resources, research, presence and influence).

Until the group can meet all eight of these criteria they will remain as an associate member, and continue to have the support and help of the IPCRG to work towards full membership.

Model

The IPCRG favours no one model; it will be dependent on the context and on the stage of development – it is likely that the model will need to change over time. However, it recognises that there are at least three models:

- A stand-alone, independent group eg PCRS (UK), CAHAG (Netherlands), GRAP (Spain) and others.
- A special interest group of a family medicine organisation eg AIMEF in Italy and also IPCRG's role as a special interest group of Wonca Europe;

- A primary care group of a specialist society eg the primary care group within ERS.

More than one group in a country

Where there is more than one group in a country that wants to be the IPCRG member, the IPCRG will enable all groups to be associate members. To become an Ordinary member, the responsibility lies with the groups to find a representative solution because IPCRG permits only one member and one vote per country. Solutions might include a number of groups forming a federation, coalition, or network, with shared leadership, with a Chair/President role that rotates after a fixed period between the different groups. Whatever solution is proposed, it must always be studied by the Board and ratified by the members at an Annual General Meeting.

If a local solution cannot be found, then the IPCRG Board may decide which group it will recommend to the members be elected based on the evidence it has of the

1. Size and scope of the groups
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3. Level of recent activity
4. Evidence of an ethos that fits with the inclusiveness, networking approach of the IPCRG
5. Their perceived independence from undue influence (eg pharmaceutical industry, politics, secondary care, commercial enterprise)

Once elected as a member

Based on the written plan, the IPCRG will agree some realistic growth targets with its members that will include objectives for:

- Membership
- Activities/resources
- Research
- Presence/influence

Every existing member will have to present this plan every two years in a rolling programme. The IPCRG will develop a simple process to review the delivery of the plan. Evidence might include:

- Membership lists
- Photographs of activities, curricula, programmes of meetings
- Annual report
- An active website
- Newsletters
- Third party reports
- Indications of contact with relevant organisations eg local GARD members, specialist society, family medicine organisation, health ministry and so on
- Publications

If the IPCRG considers that the group has met all its targets for growth then new targets for next two years will be agreed.

If the IPCRG considers that the targets are only partially met, it will agree an extension of 6- 12 months before further actions are taken.

If the IPCRG Board does not consider that the group has met its targets for growth, then it may:

1. Propose to the members that they de-select the group as an Ordinary member, but permit the group to remain as an associate member

2. Invite an existing alternative group to represent the country as an Ordinary member
3. Encourage a new group to be formed
4. Decide that it is a low priority at that stage to support the development of a primary care respiratory group in that country

This does not stop a natural process of change and renewal, where an existing group itself decides to reform.

IPCRG support

The IPCRG accords the highest priority to the development of its members. To encourage and promote this growth, some additional resources are available including:

- Free web-pages/mini web-sites hosted on our own server
- Educational materials and programmes for translation
- Funds for translations of existing IPCRG materials
- Small grants for administrative tasks
- Travel and accommodation of expert speakers and workshop leaders from our Speaker Bureau for local meetings
- The research e-faculty and other mentoring for research in primary care respiratory research-naïve settings
- Bursaries to help individuals attend IPCRG conferences to network with and learn from colleagues
- Opportunities to join IPCRG task forces and projects
- Fundraising ideas
- Multinational research network
- Web based educational programs
- Endorsement for local projects

The IPCRG's most valuable assets are its own members' projects and development. The IPCRG President and Corporate Executive will be available to help on any issue related to membership. The IPCRG may agree to put some specific resources to help members to present their materials and growth effectively and takes the responsibility to spread and share information between member countries.

Siân Williams, Executive Officer
Miguel Roman, Immediate Past President
Adopted by the Board: 21 September 2010
To be reviewed: April 2014

APPENDIX – Organisational chart

