The Founding of the International Primary Care Respiratory Group (IPCRG)

Thys van der Molen and David Price

Summary

During the First International Primary Care Respiratory Conference hosted by the UK GPIAG (General Practice Airways Group) in Cambridge, the International Primary Care Respiratory Group (IPCRG) was founded. The aims of the Group are the support and co-ordination of respiratory research in primary care, the ongoing education of primary health care providers in the field of respiratory diseases and the development of guidelines for and by primary healthcare providers. This will be achieved largely through collaboration with and support for local primary care respiratory interest groups. The next international meeting will be held in Amsterdam the Netherlands in June 2002 followed by Australia in 2004. Professor Thys van der Molen (Groningen in The Netherlands, and Aberdeen in Scotland) has been elected the first chairman of the IPCRG. He will lead the group until the meeting in 2002. Thereafter Dr John Fardy from Australia and Professor Jim Reid from New Zealand will take over, in order to organize the Australian meeting.

With the founding of the International Primary Care Respiratory Group (IPCRG) a remarkable milestone has been reached. The IPCRG was formed by consensus with representatives from over 15 countries attending the first international primary care respiratory conference.

The aim of the IPCRG is to support primary care health workers in their treatment of patients with respiratory diseases. It will do so through National Primary Care Respiratory Groups such as the GPIAG (General Practice Airways Group) in the UK; the CAHAG (CARA Huisartsen Groep; Chronic Obstructive Lung Disease General Practitioners Group) in the Netherlands; the FPAGC (Family Physician Asthma Group of Canada) in Canada; the GPAG (General Practitioners Asthma Group of the Australian National Asthma Council) in Australia; the Irish General Practitioner Group (IGPG); and similar groups in other countries including New Zealand, Denmark, France, Norway and Sweden.

Respiratory diseases, in particular asthma and COPD, are very common diseases and are a significant burden to healthcare systems comprising a large component of both acute and chronic workload. \cite{1,2,3} Although the prevalence of asthma and COPD differs between countries and within countries, epidemiological studies suggest that between 5 and 15% of all people suffer from asthma and or COPD.

Respiratory diseases, in particular asthma and COPD, are very common diseases and are a significant burden to healthcare systems comprising a large component of both acute and chronic workload. \cite{1,2,3} Although the prevalence of asthma and COPD differs between countries and within countries, epidemiological studies suggest that between 5 and 15% of all people suffer from asthma and or COPD.

Other respiratory diseases such as tuberculosis have a high prevalence in a number of countries, whereas these diseases are relatively uncommon in highly developed countries with easy access to good quality health care. \cite{4}

With the high prevalence of most respiratory diseases, it is not surprising that they are also very common in the practice of primary care physicians and primary care-based nurses. In some countries the respiratory-related consultations referred to as ‘R’ consultations in the International Classification of Diseases (ICD), in busy primary care practices may equal or exceed the number of outpatient consultations of a pulmonary specialist in a general hospital.
With the large number of general practitioners and other primary care workers in contrast to the very limited number of trained respiratory specialists, it is clear that the majority of patients with respiratory diseases will be and should be treated in primary care. The evidence for the efficiency and cost-effectiveness of primary care-based treatment, of patients with asthma and COPD in countries with strong primary health-care systems, is overwhelming. Primary care in these countries undertakes the vast majority of respiratory health care. This has real advantages for patients who have easy and almost instant access to a health-care provider in the neighbourhood and, in the countries with stable patient lists, access to a well-known provider.

That patients who have a chronic disease requiring chronic management profit from such a situation appears obvious. In 1996 a group of researchers in uptown Manhattan reported hospital admission rates up to 1003 per 100,000 for asthma alone compared with rates of approximately 400 per 100,000 in the UK. Although there certainly are differences in definitions and culture, these data emphasize the 'real-life' effectiveness for patients with less severe exacerbations in countries that provide stable easy access to primary health care and maintenance control of chronic diseases.

It is therefore a very important development that general practitioners and other primary healthcare workers recognize their role in the treatment of patients with respiratory diseases and organize themselves around this subject. One of the organizations that is extremely successful is the UK-based General Practice Airways Group (GPIAG, formerly known as the GPs in Asthma Group). Other countries have similar or related organizations each with their own agenda based on improving primary care for patients with respiratory disease.

The first target we have set for the IPCRG is to organize an international, primary care respiratory conference, every 2 years, where the best of primary care respiratory research can be presented along with major workshops about asthma, COPD, lung cancer, rhinitis, smoking cessation and respiratory infections. The first IPCRG conference will be held in June 2002 in Amsterdam.

A second major aim of the IPCRG will be to support national groups in their efforts to obtain funds for research and, it is to be hoped, co-ordinate international research projects. Research is one of the basic elements in providing evidence-based health care. Although more than 80% of respiratory disease management is provided by primary health care around the world, primary care has had only very limited access to research funding; the bulk of which is spent in hospital settings. The results of this research are often then extrapolated to primary care. However, evidence based on research in hospital settings is not necessarily valid in the family practice setting.

The third important issue for the IPCRG will be to support the development of local guidelines for the management of respiratory diseases. Many guidelines currently exist, the majority based on evidence derived from secondary care with guideline committees drawn from the same background. If a guideline committee includes a primary care physician or nurse in their board, he or she will be truly outnumbered by hospital-based clinicians and clinical inactive scientists. Guidelines should be made by those who will be using them. Local circumstances and local active health-care workers should influence the development of local guidelines to an extent that makes these guidelines workable for them.

To achieve these aims the International Primary Care Respiratory Group will attempt to put primary care development in the treatment of respiratory diseases on the agenda of many organizations related to respiratory care.

With the internationalization of the local groups, we should be able to organize the 2-yearly conferences, be a serious partner in research and the main partner in the development of new and easy-to-apply guidelines. The
membership will be the national groups committed to primary care respiratory management. Organization will be steered by members from all participant countries and will be chaired by a member of the nation that will organize the next international meeting. Co-chair will be a member of the nation that organizes the subsequent international meeting. The first President is Thys van der Molen Associate Professor of General Practice in Groningen, the Netherlands and visiting Professor of General Practice and Primary Care in Aberdeen, Scotland. The next international meeting is planned for June 2002 and the subsequent one for 2004 in Australasia which Dr John Fardy from Australia and Professor Jim Reid from New Zealand will chair. The International Primary Care Respiratory Group steering committee will have its first meeting during the ERS conference in Florence in order to put the first steps in place for the realization of the aims as stated above.

References


The Aberdeen primary care COPD research needs statement

D Price, T van der Molen

We identified a need to improve the management and outcomes for patients with Chronic Obstructive Pulmonary Disease (COPD) in primary care worldwide. Representatives from nine countries participated in the first International Primary Care Respiratory Group COPD research conference aimed at reaching consensus on the current primary care research needs for COPD.

In this document, we summarise the unmet research needs to improve the services provided within primary care for patients with COPD. These are grouped into three key themes: case identification; therapeutic interventions and delivery of care for COPD.

A Case Identification: defining COPD
What is COPD? There are a number of definitions used in secondary care and guidelines, all of them dependent on spirometry. Primary care does not always have access to spirometry, which precludes the diagnosis of COPD using these criteria in many primary care practices. Even in practices where spirometry is available many GPs will diagnose a patient as having COPD on other issues such as symptoms and history. Most primary care physicians diagnose COPD clinically including chronic bronchitis and emphysema. A possibility would be that GPs consider COPD as a part of smoking related lung disease, as defined in several Scandinavian countries. Although there are a number of arguments that support this vision we have decided to adopt the Global Initiative on Obstructive Lung Disease (GOLD) committee guidelines for our definition of COPD.

**Definition of COPD** [www.goldcopd.com](http://www.goldcopd.com)

"COPD is a disease state characterized by airflow limitation that is not fully reversible. The airflow limitation is usually both progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases."

Therefore, in order to accurately diagnose and stage COPD in accord with these guidelines, a spirometer or access to spirometry should be readily available to every primary care physician.

The GOLD guidelines consider the stage of disease definition of group 0, i.e. patients with chronic symptoms but without impairment of lung function (Table 1). These patients are of special interest for primary care. They often have severe symptoms and there is no evidence about how to treat these patients. While GOLD guidelines recommend smoking cessation as the sole intervention, patients themselves may consider this as insufficient treatment and that they need more attention.

<table>
<thead>
<tr>
<th>Stage 0</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>At risk</td>
<td>Mild COPD</td>
<td>Moderate COPD</td>
<td>Severe COPD</td>
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<tr>
<td>Normal spirometry</td>
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<td>FEV₁/FVC&lt;70%</td>
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<tr>
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<td>FEV₁/30-80%</td>
<td>FEV₁/&lt;30%</td>
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Unresolved issues

**Group 0 patients in GOLD guidelines**

- Are there any co-morbidities which encourage people to continue smoking e.g. anxiety/depression?
- What are the patient needs in this group?
- Which interventions in this group of patients will really help?
- Why is it necessary to identify these patients?
- What is the cost and benefit of identifying these patients?

**COPD in general**

- What is the influence of quality of life and symptoms in the perception of COPD and time of diagnosis?
- What are the influences of cultural differences in diagnosing COPD?

**B. Therapeutic interventions in COPD: the following key themes were regarded important in primary care:**

- How to manage patients with apparent COPD currently treated with inhaled corticosteroids (ICS)?
- Research questions related to ICS and COPD
- Education and self management plans or "Action plans"
- What do patients with COPD want and how can these needs be identified?
- Smoking cessation
- Exacerbations
- Guideline based management
- Data recording

- How to manage patients with apparent COPD currently treated with inhaled corticosteroids (ICS)?
GOLD guidelines recommend the use of inhaled steroids in patients with COPD only when the effect of ICS has been proven over a period of 6 weeks or the patient is at risk of severe exacerbations. Since many patients currently receive ICS without a formal diagnosis or having had an ICS reversibility test, physicians may feel pressurized by guidelines to stop ICS in these patients. We believe that this could lead to serious problems for some of these patients. Anecdotally, we recall a number of cases experiencing sudden exacerbations and one case of fatal exacerbation. The Isolde and Euroscop trials demonstrated an improvement on ICS, however, these trials were done using high doses of inhaled steroids and the improvement was only sustained for a period of three months.\(^4\)\(^5\) We identified the following questions regarding inhaled steroids.

ii Research questions related to ICS and COPD:

- How long should a trial of Inhaled Glucocorticosteroids last?
- What dose should it be carried out?
- Is there any difference in outcomes between conventional CFC steroids and newer HFA steroids with greater small airways deposition?
- Is it possible to stop ICS in patients with apparent COPD and what are the effects on long and short-term outcomes?
- Which disease markers predict successful ICS treatment and cessation if already commenced? Do patients with non-smoking related COPD respond differently to ICS.

iii Education and self-management plans or "Action plans"

Education and self-management plans are not always very successful, many primary care physicians and nurses regard these as complex. We believe self-management plans should be renamed as action plans. The clear consensus from research in other diseases including asthma is that these action plans need to be personalized to be effective.\(^3\)\(^4\)

Research questions:

- What is the influence of a personalized holistic action plan for patients with COPD on exacerbations, quality of life, symptoms and costs?
- What is the patient attitude towards self-management or action plans?

iv What do patients with COPD want and how can these needs be identified?

Much research has focused on therapeutic interventions although little account has been taken of the patient's agenda that may vary substantially from patient to patient. Understanding this agenda is fundamental to delivery of patient-centred care in primary care and understanding important outcome measures from the point of view of the patient.

Research needs:

- What are patients' beliefs about COPD/respiratory disease and smoking and how does this affect their attitudes to any form of intervention?
- What are the patients' needs with regard to symptom relief?
- Which symptoms should we focus on with therapeutic interventions in clinical practice and research?
- Are health care professionals informed enough about the needs of patients with COPD?
- What do patients consider the most important improvement that they could have as related to their disease?
- What is the impact of depression, neuroticism, anxiety, and cognitive failure on their perception and coping with COPD?
- Does it improve outcomes if we consider quality of life and depression as influential topics within our treatment plans?
- What are the relations of various patient-focused outcome measures?
- What are the goals of patients for treatment of their COPD?
- Can these goals be used for evaluation of treatment response and how should this be done?
v Smoking cessation

A number of significant barriers exist regarding general practitioners undertaking smoking cessation. We need to research effective ways of undertaking smoking cessation within “real-life” clinical practice.

Research that may help:

- Is it possible to develop an effective short “30 second” method of smoking cessation appropriate for use in primary care consultations?
- Why are guidelines for smoking cessation not followed?
- What do patients want when they visit a primary care physician in relation to smoking behaviour?
- What is the effect of case finding in a general practice and does it have any influence on smoking behaviour?
- Furthermore does case finding followed by proper disease management have any influence on morbidity and mortality due to COPD?

vi Exacerbations

After decades of research and debate we have not reached a proper consensus on defining and treating an exacerbation of COPD. Exacerbations are generally considered to be an increase of breathlessness with increased quantity and purulence of sputum.

We therefore propose the following research questions:

- What is an appropriate and useful definition of an exacerbation of COPD in primary care?
- When should we use antibiotics and/or steroids during an exacerbation of COPD?
- And how can this be incorporated into patient management/action plans?

vii Guideline based management

With the advent of international guidelines for the management of COPD it is fundamental that we examine a number of questions related to guideline implementation and effectiveness in primary care:

- What is the impact of guideline management on outcomes for patients with asthma?
- Can adherence to effective guidelines be improved in primary care?

viii Data recording

Currently no clear consensus exists on what is the most important data to collect in COPD management and it is therefore if we wish to audit care in primary care that we define an evidence based minimum dataset for the management of COPD.

C. Delivery of Care

Debate currently focuses on who should deliver care in COPD and to whom. Potential different models are shown in figure 1 with varying levels of specialism in primary and secondary care as well as the use of shared care between generalists and specialists as well.

Research needs:

- What are the necessary components of successful quality care in primary care?
- What equipment is required?
- What components of care can and should be delivered in every general practice?
- Can specialist care be effectively and cost-effectively delivered in primary care?
- Who should be referred to specialist care either in primary or secondary care?
• What equipment is necessary for differing levels of care in primary care?
• How is quality control maintained in primary care?
• What is the impact of differing health care systems in terms of health care costs and patient outcomes?
• What are the costs of differing models?
• Should the generalist GP deliver routine care for patient with COPD or is it a disease for secondary care?
• What system of monitoring and structured recall is appropriate for differing severities of COPD?
• Can pulmonary rehabilitation be delivered in primary care and is it effective in this setting?

Figure 1: Models of delivery of COPD Care

Conclusions and project development

The Aberdeen meeting has identified key essential research needs for ensuring effective care for patients with COPD in primary care. We have developed four strategic groups to develop detailed research agendas for the areas outlined above including literature reviews to lay the groundwork for future research work to answer this research needs statement. This groundwork will be completed and published during the autumn. A follow-up conference is planned for March of 2002 to evaluate progress on designing research proposals and to feedback on some pilot research projects that are being undertaken.

REFERENCES


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