Systems for the management of respiratory disease in primary care – an international series: United Kingdom

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Abstract

**Introduction:** The UK National Health Service (NHS) is essentially publicly funded through general taxation. Challenges facing the NHS include the rise in prevalence of long-term conditions and financial pressures.

**National policy trends:** Political devolution within the UK has led to variations in the way services are organised and delivered between the four nations.

**Primary care respiratory services in the UK:** Primary care is the first point of contact with services. Most respiratory conditions are managed here, including prevention, diagnosis, treatment and palliative care.

**Epidemiology:** Respiratory disease accounts for more primary care consultations than any other type of illness, with 24 million consultations annually.

**Access to care:** Equitable access to care is an ongoing challenge: telehealthcare is being tried as a possible solution for monitoring of asthma and COPD.

**Referral and access to specialist care:** Referrals for specialist advice are usually to a secondary care respiratory physician, though respiratory General Practitioners with a Special Interest (GPwSIs) are an option in some localities.

**Conclusions:** Prevalence of asthma and COPD is high. Asthma services are predominantly nurse-led. Self-management strategies are widely promoted but poorly implemented. COPD is high on the policy agenda with a shift in focus to preventive lung health and long-term condition management.

Keywords United Kingdom, respiratory disease, primary care, management, systems, policy, funding

Contents

Background ................................................................. 24
Introduction .......................................................... 24
The organisation of health services ........................................... 24
Challenges for the next 60 years ........................................... 25
Primary care respiratory services in the UK .............................. 26
Prevention .......................................................... 26
Guidelines and management pathways ................................... 26
Diagnosis and disease registers ........................................... 26
Self-care .......................................................... 26

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Background

This paper on the current provision of primary care services for patients with respiratory disease in the United Kingdom (UK) is the fifth in a planned series of international reviews. In keeping with the aims and objectives of the Primary Care Respiratory Journal, the editors commissioned this series of papers to enable clinicians and health service managers to compare and learn from different systems of primary care management for patients with respiratory disease around the world. Each of the papers in the series so far (see Box 1) follows a similar format, and includes information on national policy and models, epidemiology, access to care, facilities available, and future developments. By summarising and comparing how different countries provide primary care for patients with respiratory disease we hope to stimulate debate and inform the future development of policies aimed at improving the care worldwide for people with respiratory disease.

Box 1: PCRJ series on the management of primary care respiratory disease throughout the world: papers to date.


Introduction

The UK’s National Health Service (NHS) was established in 1948 as a publicly funded healthcare system to provide comprehensive healthcare services free to the entire population at the point of delivery. Historically, funding has mainly come from general taxation and this remains largely the case, although some personal charges, including prescription charges, were introduced in the 1950s. As with all healthcare systems, demographic changes, technical advances, and financial constraints are putting increasing pressure on services. Ways of making healthcare more cost-effective and efficient are thus a constant government preoccupation.

The organisation of health services

A founding concept of the NHS was that all people in the UK should be registered with a general practitioner (GP or ‘Family Doctor’) close to their home who was responsible for providing, or arranging for others to provide, all patients’ healthcare needs. By contrast, specialists were hospital-based, receiving referrals from, and reporting back to, the patient’s own GP, who held the patient’s complete medical record. This core division of services remains, though arrangements have become more complex in recent years with the development of new roles (e.g. specialist nurses, GPs with a Special Interest (GPwSIs), community-based specialists), and in response to the expectations of an increasingly mobile, 24-hour a day society. In general, public satisfaction with their GP and general practice remains high.

GPs have traditionally been self-employed, working in partnerships and contracting their services to the NHS, though recent changes have allowed the employment of salaried GPs and the development of diverse arrangements either to address the needs of specific communities (e.g. the homeless) or in under-doctored areas. Most practices employ practice nurses and/or nurse practitioners, so that multidisciplinary working is now the norm. In a recent initiative, large primary care facilities (‘polyclinics’) offering many of the diagnostic and out-patient services traditionally provided in secondary care are being actively promoted. These are not always welcomed as they may compete with local general practices.
Primary care, though no longer exclusively provided by GPs, remains the first point of contact with most NHS services. Nurse practitioners may provide minor illness services within primary care practices, and minor injury units are run in some large practices or community hospitals. In England and Wales, ‘walk-in centres’ (which are normally nurse-led) are sited in major cities to provide a convenient open access option – for example, for people away from home and those not registered with a permanent GP. Since the introduction of the new General Medical Services (GMS) Contract in 2004, out-of-hours responsibility has been transferred to locally run ‘Out-of-Hours’ services sometimes operated in partnership with the telephone- and Internet-based services NHS Direct (England), Galw IECHYD Cymru (Wales), and NHS24 (Scotland).

The concept of a UK-wide NHS is now outmoded. Since political devolution in 1999, health policy in the four nations (England, Scotland, Wales and Northern Ireland) has diverged (see Table 1), reflecting different political, philosophical and demographic conditions. NHS England, driven by Government targets and financial incentives, has pursued the internal market in which performance-managed contracts are commissioned from an increasing range of private and public provider organisations. The recently elected Government’s White Paper on health in England proposes giving more power and responsibility for commissioning services to local consortia of GP practices. NHS Scotland and Wales have in contrast promoted a more collaborative approach, engaging clinicians in decisions about resource allocation. Some differences (such as abolition of prescription charges in Wales, Scotland and Northern Ireland) have led to well publicised anomalies, especially in border areas. Scotland, unlike the rest of the UK, has in recent years promoted the development of Managed Clinical Networks (MCNs), and most Scottish health authorities now have a respiratory MCN with multi-professional, multi-disciplinary and multi-agency representation to co-ordinate, develop and support integrated care across service and professional boundaries.

### Challenges for the next 60 years

The 60th anniversary of the NHS in 2008 occasioned much reflection on its achievements and failures, and speculation regarding the next 60 years. The general consensus appears to be that there are aspects to be celebrated – including primary care services – particularly in comparison to other healthcare systems. Despite the different policies between the four nations, many overarching challenges remain and these are summarised in Box 2.

**Box 2: Current challenges facing the NHS.**

- Reducing the persistent inequalities in health and access to health care.
- Reducing variations in the quality of care.
- Improving quality, increasing adherence to evidence-based guidelines, and reducing variability in service provision.
- The ageing population and the consequent increase in long-term medical conditions and co-morbidity.
- Shifting the focus of service delivery from the traditional sectors to the provision of care packages that integrate care across primary, secondary, tertiary and social care sectors.
- Integrating care for patients with multiple co-morbid conditions.
- The potential impact of climate change on respiratory health.
- Continual political and financial pressures with cost containment.
- An ageing health professional workforce.
- Reform fatigue among staff.
- Reducing the current budget deficit without affecting healthcare.

### Table 1. Policy and organisational characteristics of the four countries of the UK.

<table>
<thead>
<tr>
<th></th>
<th>England</th>
<th>Wales</th>
<th>Scotland</th>
<th>N Ireland</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population (millions)</strong></td>
<td>50</td>
<td>3</td>
<td>5</td>
<td>1.7</td>
</tr>
<tr>
<td><strong>Organisational characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provider markets, patient choice, pluralism in delivery and providers paid by activity</td>
<td>From 2006</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Integration of health and social services</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Commitment to election for local NHS governing bodies</td>
<td>No</td>
<td>No</td>
<td>Yes (in 2007 but not yet implemented)</td>
<td>No</td>
</tr>
<tr>
<td><strong>Performance regimes</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Targets for waiting times</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Annual public reporting of performance in a system of ‘naming and shaming’</td>
<td>By star ratings from 2001-2005</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Charges and entitlements</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free personal care services for the over 65s</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Free prescriptions</td>
<td>No</td>
<td>Yes</td>
<td>To be implemented</td>
<td>To be implemented</td>
</tr>
</tbody>
</table>
Key policy trends underpinning current development in the NHS in response to these challenges include:

- Developing new competencies and different skill sets to deliver more complex models of care; community nurse and pharmacist roles in respiratory care are notable developments.
- More flexible working patterns.
- Greater use of information technology such as telemedicine, Internet information provision, use of telephone and email consultations.
- Shifting services from secondary to primary care i.e. ‘closer to the patient’, offering patients information to enable them to choose between available treatments, and where and from whom they receive services, involving the patient not only in their own care but also in the design of local services.

**Primary care respiratory services in the UK**

Primary care is at the forefront of the NHS response to the global challenge of providing care for an ageing population with an increasing burden of long-term conditions. The 2004 GMS contract introduced an innovative ‘Pay for Performance’ scheme, the Quality and Outcomes Framework (QOF). This rewards general practices that achieve targets set over a wide range of clinical indicators by providing financial incentives to encourage accurate diagnosis, maintenance of disease registers and proactive care of people with long-term conditions. Of the 1,050 points available, 35 are allocated to asthma indicators and 30 to COPD with additional generic points for providing smoking cessation advice. Approximately 20% of general practice income is linked to QOF. Payments are related to prevalence as well as performance, but a typical GP’s gross income increased by £23,000 in the first year of the QOF, though the costs of providing the additional services were borne by the practitioner. Examples from respiratory care include confirmation of chronic obstructive pulmonary disease (COPD) with spirometry, and annual reviews for people with asthma (see Table 2). Analysis of the QOF submissions suggests that this has improved the process of care.

As a major cause of hospital admissions, respiratory disease (specifically COPD) is seen as a priority for the NHS. In England, the publication of a National Strategy sets out for the first time evidence-based pathways for common and important conditions (including asthma and COPD), designed as a resource for clinicians and those developing care in England and Wales.

**Guidelines and management pathways**

The UK has a long history of internationally recognised guideline development since the first British Thoracic Society (BTS) asthma guideline was published in 1990. The Scottish Intercollegiate Guideline Network (SIGN) (which now co-produces the British asthma guideline with the BTS) was amongst the earliest groups to use a rigorous, evidence-based, guideline development process. More recently, the National Institute for Health and Clinical Excellence (NICE) in England has adopted a similar methodology in their development of COPD guidelines, though they also include a cost-effectiveness analysis as part of a drive to reduce the informal rationing and geographical variations in availability of treatments and services that was a particular concern in the late 1990s. Launched in 2009, NHS Evidence is a search engine which enables everyone working in health and social care to identify and access a wide range of health information. ‘Map of Medicine’ (available from www.mapofmedicine.com) is an electronic visualisation of evidence-based pathways for common and important conditions (including asthma and COPD), designed as a resource for clinicians and those developing care in England and Wales.

**Diagnosis and disease registers**

All primary care practices in the UK maintain computerised disease registers. Inclusion of lung function as an indicator in the QOF has resulted in a rapid rise in the number of primary care practices offering spirometry such that about 90% of people on general practice COPD registers have now had their diagnosis confirmed with spirometry.

**Self-care**

Supported self-management for people with long-term conditions in the UK has been described as less effective than in other countries. It remains, however, a key policy directive. By 2011, as part of the drive to facilitate self-care, it is intended that all people with long-term conditions in England...
will have a Personalised Care Plan (PCP). In the context of asthma, this plan will focus on evidence-based ‘action plans’. In the more complex scenario of severe COPD, action plans for self-management of exacerbations will be supplemented by information about multidisciplinary clinical and social services.

This ‘drive to facilitate self care’ extends to other parts of the UK, but unlike in England, there are no similar targets relating to care plans in Scotland. Patient organisations (e.g. Asthma UK www.asthma.org.uk and the British Lung Foundation www.lunguk.org) are important sources of information for patients (including Asthma Action Plans and COPD self-management resources) as are local support groups (e.g. Breath Easy Groups, which are voluntary peer groups supported by the UK charity the British Lung Foundation).

**Regular review**

The QOF rewards primary care practices financially for performing annual reviews for people with asthma and COPD. In the case of asthma the requirement is for a single coded entry for an ‘asthma review’, though the QOF guidance documentation details the specific functions (such as assessing control, checking inhaler technique and providing self-management advice) that the assessors who visit practices...
annually to verify performance might look for to substantiate claims. Although this approach has been criticised as a ‘tick box’ exercise, there is evidence that the process has facilitated pro-active care with the potential to improve outcomes.\textsuperscript{33,38} The introduction of the Medical Research Council’s Dyspnoea Score as a requirement for the annual COPD review represents a step towards targeting outcome rather than process measures.

Palliative care
Extending palliative care services to people dying with non-malignant conditions is a UK-wide priority,\textsuperscript{48} and there is considerable interest in how current services may be adapted to meet the needs of people with very severe COPD.\textsuperscript{40} The pivotal role of primary care in providing care for people with long-term conditions suggests that GPs and community nurses will continue to have a significant role in provision of supportive end-of-life care,\textsuperscript{35} supported by education and advice from specialist palliative care teams.

Epidemiology of respiratory disease in the UK
In the UK, respiratory disease accounts for more primary care consultations than any other type of illness: there are 24 million respiratory consultations and 51 million prescriptions issued annually.\textsuperscript{19}

Approximately one in nine in the UK has been diagnosed with asthma.\textsuperscript{60} Prevalence from QOF submissions of ‘active asthma’ (i.e. people with a diagnosis of asthma who have had a prescription for an asthma medication in the previous year) has remained fairly constant at 5.8%, though, unusually for disease registers, this is a ‘fluid’ population: one large practice reported a 20% turnover over in a year as patients with an asthma diagnosis became, or ceased to be, ‘active’ as a result of the variability of the condition.\textsuperscript{34}

Prevalence of COPD varies according to deprivation status, but an average of 1.5% of the population are registered as having COPD in England.\textsuperscript{51-53,61} Most diagnosed COPD patients have severe or very severe COPD according to the 2010 NICE classification\textsuperscript{46} (which now categorises COPD in line with international guidelines\textsuperscript{65}), leading to calls for screening or case-finding to identify the ‘missing millions’ with milder disease.\textsuperscript{40}

The annual incidence of community acquired pneumonia is 5-11 per 1000 adult population, though this is less than 10% of the lower respiratory tract infections managed by GPs.\textsuperscript{63} The incidence of pulmonary tuberculosis has increased over the last decade, the majority of cases occurring in migrants from the Indian sub-continent and sub-Saharan Africa, the immuno-compromised and homeless people.\textsuperscript{64}

Access to care
People with respiratory long-term conditions value flexible access to a known and trusted professional who can provide, or co-ordinate, care on behalf of themselves and their family carers.\textsuperscript{54} Traditionally this was the role of GPs, but the need to develop pro-active care for people with long-term conditions has stimulated the evolution of a broad range of primary care professionals to provide, or support chronic, ongoing respiratory care.

The primary care contracts, which remunerate practices for both the quality and activity they undertake, have encouraged GPs to delegate the management of long-term medical conditions to appropriately trained nurses. In the UK, most patients with airways diseases are therefore managed in primary care by practice nurses working in partnership with their GP colleagues. The growth in pro-active care in the last 20 years may have contributed to the observed reduction in unscheduled appointments for asthma,\textsuperscript{66} though the more recent plateauing of death rates remains a concern.\textsuperscript{67}

New technologies are offering innovative approaches to the challenge of providing access to care.\textsuperscript{68-70} Telephone reviews for asthma are an established option,\textsuperscript{26,27,39} and the potential for mobile technology in monitoring patients with asthma is being explored.\textsuperscript{71,72} Tele-monitoring is being introduced as a means of reducing COPD admissions, though trials of this approach are still on-going.

Facilities in primary care
Common respiratory conditions can and should be managed predominantly in primary care, including prevention, diagnosis, treatment and palliative care.\textsuperscript{74} People with asthma are more likely to have their condition managed in primary care in the UK than in most other countries.\textsuperscript{75} The QOF supports this approach by providing financial rewards that have enabled most UK practices to invest in spirometers, though there is concern that this initiative is not supported by adequate staff training. For example, a national survey revealed that only 12% of nurses undertaking spirometry had undertaken accredited training and fewer than half (49%) of those diagnosing and managing COPD had undertaken specialist training.\textsuperscript{76} The recently published standards for diagnostic spirometry in primary care emphasise the importance of appropriately calibrated and serviced equipment, operated safely by trained professionals with accredited and maintained skills, and correctly interpreted by healthcare professionals.\textsuperscript{69}

Most patients with allergies are managed in primary care, and access to specialist services is limited. A recent survey of GPs found that only 9% had received allergy training.\textsuperscript{77} Allergy testing, essential to accurate diagnosis and treatment, is rarely conducted in primary care: skin prick testing is only rarely available\textsuperscript{78} and specific IgE testing although widely available is rarely used. Practices have open access to blood tests and radiology services, oximetry is increasingly available, but in some
areas investigations such as CT or MRI scanning may require specialist referral.

**Professional organisations**

The UK clinical and academic communities have considerable interests in collaborative ventures to promote respiratory care.

The Primary Care Respiratory Society UK (PCRS-UK) (formerly known as the General Practice Airways Group - GPAG) was formed in 1987 and has been a driving force, both locally and nationally, in the development of respiratory care in the community, primarily in the UK, but also abroad. The PCRS-UK represents primary care health professionals interested in delivering the best standards of respiratory care through research, education and influencing policy. The group is one of the founding members of the International Primary Care Respiratory Group (IPCRG), which supports international efforts to develop research, education and clinical care in respiratory disease. A range of practical resources is available on the organisation's web-site (www.pcrs-uk.org), and the PCRS-UK's peer reviewed journal, the Primary Care Respiratory Journal (www.thepcrj.com), is one of a very few primary care speciality journals listed on PubMed.

IMPRESS is a clinician-led joint venture between the BTS and PCRS-UK, which maintains a website targeted at commissioners of health care, managers and clinicians who wish to develop high quality patient-centred respiratory services, integrated between primary and secondary care (www.impressresp.com).

The Royal College of General Practitioners (RCGP) has recently prioritised respiratory and allergy care, with the appointment of respiratory and allergy Clinical Champions. The scheme aims to support implementation of the National Strategy for COPD, drive rapid uptake of the new guidelines, and encourage Primary Care Organisations (PCOs) to take action to improve allergy services locally. Quality markers of respiratory care in general practice are being developed.

The UK Respiratory Research Collaborative (UKRRC) was launched in 2006 to promote research in respiratory care. (www.brit-thoracic.org.uk/research/ukrrc.aspx). It has primary care representation and has prioritised areas pertinent to primary care, including investigating the best care and treatment strategies for asthma and COPD. A range of primary care academic departments have particular interest in respiratory disease, including the Universities of Edinburgh (allergy and respiratory research), Aberdeen (primary care respiratory medicine), Cardiff (respiratory infections), Queen Mary, University of London (respiratory health (including TB) in ethnic groups) and Peninsula Medical School (COPD and community-based pulmonary rehabilitation).

Educational support for health professionals is available from independent charities such as Education for Health (www.educationforhealth.org) and Respiratory Education UK (www.respiratoryeduuk.com). These organisations offer distance, blended and e-learning modules in the prevention, early diagnosis, appropriate treatment and effective management of respiratory diseases from paediatric to end-of-life care.

**Referral and access to specialist care**

UK political initiatives such as ‘care closer to home’, the ‘choice’ agenda (which ostensibly offers patients the opportunity to choose where they go for specialist care), target waiting times, financial constraints, and new professional roles, have all influenced traditional referral arrangements, though access to secondary care still requires a referral from a primary care clinician (usually the GP). Referrals for specialist advice can be to a secondary care respiratory physician, or in some localities (mainly in England) respiratory GPwSIs are providing community-based referral services for specific conditions such as COPD or asthma. Although the formal accreditation process (normally based on a portfolio of professional training and experience) addresses the governance requirements for the delivery of a clinical service, many GPwSIs also have an important strategic and training role within their locality. In 2006, 38% of PCOs had, or were considering developing, a respiratory GPwSI service.

As part of the National Programme for IT, patients in England are now able to ‘Choose and Book’ their own specialist appointments, taking into account their personal preferences as well as information about referral options. This initiative has attracted diverse views from professionals who generally welcome the principle of patients booking their own appointments, but who have expressed concern about the usability of the system. However, the recent White Paper in England sets out the intention to extend the Choose and Book system, which in some areas includes the addition of ‘Referral Management Systems’ whereby GPs and nurses triage referrals to specialists, either accepting, diverting them to a more appropriate service or returning them to the GP.

Although most areas of the UK have a pulmonary rehabilitation service, in many localities provision is inadequate and there is growing interest in developing cost-efficient community-based services. The increasing complexity of services, with professionals adopting new specialist roles and providing services in new ways has increased the challenge of ensuring integrated care for the individual patient.

**Conclusions**

Primary care services in the UK remain highly valued by patients. Care for patients with asthma, COPD and respiratory infections constitute a large proportion of primary care activity in the UK, where prevalence of these conditions is notably high. Organisation of asthma services has been transformed in recent years by the development of proactive nurse-led care. Despite widespread promotion of self-management strategies,
implementation has been limited. The prominence of COPD on the policy agenda promotes an increasing shift in focus to a more proactive, preventive lung health strategy and long-term condition management. The recent formation of a coalition government following the general election in the UK, together with the unprecedented budgetary deficit and plans to shift much of the long-term care of patients into the community, has already given rise to proposals which will radically change primary care provision of healthcare in the future.

Conflict of interest declaration

AW, HP, MF, GH have no conflicts of interest to declare. MILL is the Editor Emeritus of, AS is Joint Editor-in-Chief of, and HP is an Associate Editor of, the PCJ. They were not involved in the editorial review of, nor the decision to publish, this article.

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A Worth et al.
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