Allergy: the unmet need

A blueprint for better patient care

A report of the Royal College of Physicians Working Party on the provision of allergy services in the UK

Royal College of Physicians

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Foreword

Allergy is a major public health problem in developed countries. In the UK over the last twenty years, the incidence of common allergic diseases has trebled, giving this country one of the highest rates of allergy in the world. In any one year, 12 million people in the UK (one-fifth of the population) are now likely to be seeking treatment for allergy. Potentially life-threatening but previously rare allergies, such as peanut allergy which now affects one in 70 children, are increasing. But despite the epidemic proportions of the disease, the health service is failing to meet the most minimal standards of care – far less clinical governance.

This report shows clearly that there are far too few specialist allergists to meet the needs of the population, either in terms of delivering direct care in dedicated allergy centres, or in providing training for other specialists, general practitioners and practice nurses. It should be possible for milder cases of allergy to be recognised and treated in primary care so that only the more severe and complex cases need referral to a consultant. However, without the appropriate infrastructure and training this is not possible – and the health service will continue to fail to keep pace with the needs of allergy patients.

In publishing this report, the Royal College of Physicians aims to put allergy higher on the healthcare agendas of the Department of Health and planners and managers. We have made proposals for a much improved allergy service which, given the will to change and understanding of the problems faced by allergy patients, will result in more consultants, a network of accessible centres around the country, and much improved and wider training of those who care for patients. These proposals require urgent action.

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Professor Carol Black
President,
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Allergic disease is one of the major causes of illness in developed countries and its prevalence is increasing steadily. In the UK, allergic disease affects about one in three of the population. In 13- to 14-year-old children, 32% report symptoms of asthma, 9% have eczema, and 40% have allergic rhinitis. The UK ranks highest in the world for asthma symptoms, with a prevalence 20-fold higher than that of Indonesia, and is also near the top of the world ranking for allergic rhinitis and eczema. High and increasing trends are also apparent in nut allergy, anaphylaxis, occupational allergy (eg latex), and allergic reactions to drugs.

Although genetic susceptibility is an important risk factor for allergic sensitisation and its expression as disease in different organs, the current allergy ‘epidemic’ is a consequence of our changing environment. Increased exposure to allergens and air pollutants, over-use of antibiotics and other drugs, reduced fruit and vegetable intake, reduced early life exposure to bacterial products, and an alteration in bacterial colonisation of the gut have all been blamed.

Allergy is an important branch of medicine and specialisation is required to provide a high-quality service for the diagnosis and treatment of allergic disease. Unfortunately, in the UK such a service has not developed. Allergic disease now causes problems of increased complexity and commonly involves several organ systems, so patients are often referred to a succession of different specialists, resulting only in confusion. Instead, a single referral to an allergy specialist would be both effective and cost saving. General practices and hospitals usually have little, if any, resources for establishing the presence (or absence) of sensitisation to specific allergens. In consequence, most allergic disease is treated with drugs, with little attention being paid to establishing causative agents and allergen avoidance strategies.

There is a major shortage of allergy specialists, with only six fully staffed allergy clinics in the UK, that have developed mainly around research interests. Allergy barely features in the undergraduate medical curriculum, and the lack of specialists means virtually no clinical training is available. Opportunities for postgraduate clinical training are limited. Knowledge of good allergy management in practice is therefore minimal or non-existent.

The allergy charities, along with NHS Direct, are inundated with telephone enquiries from a public desperate for help with their allergy problems. The severity of their symptoms, with attendant high morbidity, has forced the public to look outside the NHS. This has led to the proliferation of dubious allergy practice in the field of complementary and alternative medicine, where unproven techniques for diagnosis and treatment are used. In 1992, the Royal College of Physicians (RCP) produced a report, Allergy: conventional and alternative concepts, which drew attention to the importance of good clinical practice in allergy and the dangers of relying on practitioners of complementary and alternative medicine to deliver a competent allergy service to the public. In 1994, this was reinforced by a second report, Good allergy practice: standards of care for providers and purchasers of allergy services within the NHS. Although both reports were well received, their impact on improving the provision of allergy services in the NHS has been limited.
The impact of allergic disease, the dearth of NHS services, and wide differences in disease management across the UK created the impetus for this third RCP report. In drawing attention to the high and ever-increasing prevalence and complexity of allergy, the disease burden this creates, and the lack of any cohesive approach to delivering an adequate clinical service within the NHS, this report highlights the unmet needs of the many patients who suffer from allergy, and the impaired quality of life that they endure. With the influence that the public now exerts over their healthcare, the increase in multi-professional working, and the political will to provide further resources for the NHS, the time has come to make a determined effort to improve clinical services for patients with allergic disease in the UK.

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References

Executive summary and recommendations

Background

This report discusses the implications for the NHS of the dramatic increase in allergy in recent years, including severe life-threatening and multi-system allergies. Drawing on recent research on the prevalence of allergic disease in the UK, it reveals the gulf between the need for effective advice and treatment and the lack of appropriate professional services, and proposes a strategy to address this. There is an urgent need for these proposals to be implemented, given that the incidence of allergy and related diseases is almost certain to continue to rise. The report is therefore addressed to the Department of Health, primary care trusts, hospital trusts, as well as all healthcare professionals involved in allergy care, including those in primary care.

Allergy and allergy specialists

Allergy specialists deal with a wide range of disorders, such as rhinitis, asthma, urticaria, angioedema (including hereditary angioedema), eczema, anaphylaxis, and allergy to food, drugs, latex rubber and venom. They also have the expertise to exclude allergy as a diagnosis, allowing the patient to proceed with other appropriate investigations.

The above disorders may result from generation of IgE antibody (allergic antibody), but the same disorders and symptoms, eg anaphylaxis, drug or food allergy, can occur through mechanisms that are independent of IgE. Whilst symptoms may be restricted to one organ – for example the nose in hay fever – in many allergic disorders there are systemic effects that involve several different sites in the body.

Allergy specialists undergo a long period of training to acquire the knowledge and experience needed to correctly diagnose and treat both IgE- and non-IgE-mediated allergies.

An increasing problem

Allergy is an increasing problem in the UK for three main reasons:

*Increased incidence* The incidence of allergy has increased dramatically in the UK in recent years and is still rising. Recent studies put the rise as approximately three-fold in the last 20 years, giving the UK one of the highest rates of allergic disease in the world. The latest estimates suggest that one-third of the total UK population – approximately 18 million people – will develop allergy at some time in their lives.

*Increased severity* The nature of allergic disease has also changed, so a number of severe and potentially life-threatening disorders, which were previously rare, are now common. As part of the increase in incidence, more children are now affected, particularly by previously little-known food allergies, such as peanut allergy. These are also among the most serious allergies, and accurate diagnosis, advice and treatment are vital.

*Increased complexity* Another development is that patients now usually have disorders affecting several systems. For example, a child with peanut allergy often also has eczema,
rhinitis and asthma – so-called ‘multi-system allergic disease’. Poorly controlled asthma in a patient with nut allergy is a risk factor for life-threatening or fatal reactions.

The following statistics, taken from the body of the report, illustrate these changes (some of these statistics are underestimates, since allergy can remain undiagnosed):

- Asthma, rhinitis and eczema have increased in incidence two- to three-fold in the last 20 years.
- Anaphylaxis, a severe and potentially life-threatening reaction, occurs in over one in 3,500 of the population each year as a result of exposure to substances to which the sufferer is allergic. Hospital admissions because of anaphylaxis have increased seven-fold over the last decade and doubled over four years.
- Food allergy is increasingly common and is the most common cause of anaphylaxis in children. Peanut allergy, the most common food allergy to cause fatal or near-fatal reactions, has trebled in incidence over four years and now affects one in 70 children in the UK. Yet only 10 years ago this was a rare disorder.
- Drug allergy is also increasingly common. Adverse drug reactions account for 5% of all hospital admissions in the UK. Up to 15% of inpatients have a hospital stay prolonged as a result of drug allergy. These figures do not include the majority of drug allergies, which occur in primary care and remain undiagnosed and unrecorded.
- Some 8% of healthcare workers now have an allergy to latex rubber, which in some cases can lead to anaphylaxis. Yet until 1979 only two cases of latex allergy had been reported.
- Allergic disease currently accounts for 6% of general practice consultations, 0.6% of hospital admissions, and 10% of the GP prescribing budget. The cost (in primary care, excluding hospital services) to the NHS is £900 million per annum.

Current deficits in NHS allergy services

Responsibility for the treatment of allergic disease in the NHS is shared between GPs and hospital services. However, there are three major problems:

1. Even before the recent increases in the incidence of allergic disease, there was a shortage of specialists with the expertise required to give the necessary advice and treatment, and to lead the search for ways to contain the ‘epidemic’:

- Across the whole country, only six major centres staffed by consultant allergists offer a full-time service with expertise in all types of allergic problems. A further nine centres staffed by allergists offer a part-time service.
- The remaining allergy clinics in the UK – the majority – are run part-time by consultants in other disciplines. However, they do not have the facilities to cope with the rising tide of allergies or with the problems posed by severe or multi-system allergic disorders.
- There is a marked geographical inequality in service provision, as most allergy specialists are based in London and the south-east. Services are extremely poor in the rest of the country.
- Overall, the provision of consultant allergists is approximately one per 2 million of the UK population, compared with rates of around one per 100,000 for mainstream specialties such as gastroenterology, cardiology, etc.
2 Allergy services in hospitals have traditionally been provided by different specialists according to the organ system affected; for example, allergic asthma is often managed by chest physicians, allergic skin disorders by dermatologists, and allergic rhinitis by ENT specialists. However, **most organ-based specialists have no training in allergy**. In addition, the development of severe, multi-system and non-organ-based disorders means that allergy now has to be considered as a health issue in its own right.

3 Currently, many allergy cases are dealt with by GPs, but because allergy has only recently become such a major problem, **the majority of GPs have no clinical training in allergy**. Furthermore, the shortage of specialists means that GPs often have no ready source of expert advice. The skill base needed to develop allergy services which are led directly from primary care is currently absent.

As a result of the problems outlined above, patients generally find great difficulty in obtaining good advice on allergy. The health service lacks the infrastructure to close the gap between needs and services. Thus, the most common reasons for calls to helplines run by allergy charities, eg the Anaphylaxis Campaign or Allergy UK, are:

- 'My GP does not know about allergy.'
- 'There is no allergy service near me.'
- 'The “allergy clinic” I was referred to did not know how to help me.'

**A strategy for addressing the problems**

1 Allergy needs a ‘whole system’ approach in which allergy is treated as a condition in its own right, and not as a series of diseases depending on the organ system involved.

2 The number of allergy specialists is totally insufficient to meet the need. Proper provision of allergy specialists would mean better access, diagnosis and advice for patients, and would provide a knowledge base from which primary carers could develop their services.

3 A more effective partnership is required between allergy specialists and the primary carers, who will need to provide the bulk of the day-to-day support for people with allergy. A hub-spoke network with allergists supporting GPs and organ-based and other specialists in local hospitals should be developed.

**Recommendations**

The recommendations set out in this report are intended to form the basis for the development of a coordinated service over the coming decade. It is envisaged that such a service will progressively become primary care led, with expertise available from the hospital setting for more severe and complex problems. However, given the current lack of training and knowledge in primary care, initially an allergy service would need to be led by allergy specialists. It follows that there must first be an increase in numbers of allergy consultants, as detailed below. Within the hospital sector, the increase in multi-system and severe allergic disease indicates the need for consultant allergists who can provide a ‘one-stop-shop’ approach for patients.
General recommendations for an improved allergy service

1 The provision of allergy care in the NHS must be led by specialists trained in allergy so that appropriate standards of care can be achieved and maintained. Given the scale of what amounts to a national epidemic, the front line for allergy management must be within primary care. However, with virtually no primary care skill base to work from, clinical leadership must come initially from specialist centres. They will need to take on the dual role of diagnosis and management of the most complex cases, and of supporting the development of capacity within primary care.

2 The NHS therefore needs to move forward on two fronts. As an essential first step, more consultant posts and funded training posts in allergy are required. Specialist allergists must become the core leadership for a national training and clinical development initiative for the whole service. They must also provide the essence of a genuinely national allergy service for the NHS. The creation of these posts, and their appropriate service development context, requires a recognition of need by the Department of Health, the Workforce Numbers Advisory Board, primary care trusts, regional commissioners and trust managers.

3 The report proposes the setting up of appropriately staffed regional allergy centres evenly distributed across the whole country. Based on the service models which exist in those parts of the UK fortunate enough to have established specialist centres, they will give equality of access to appropriate allergy services for adults and children in all parts of the country. They will also provide expertise and lead the development of other local services, networking with organ-based specialists and GPs.

4 Regional commissioning for specialist allergy must also be implemented. This will require central direction.

The specific recommendations of the report are grouped below under five headings.

Specific recommendations

Regional allergy centres

5 The working party endorses the recommendations of the British Society for Allergy and Clinical Immunology (BSACI) that each of the eight NHS Regions in England (as configured in 2001, each with a population of approximately 5–7 million), as well as Scotland, Wales and Northern Ireland, should have an absolute minimum of one regional specialist allergy centre.

6 Staffing levels required to set up a new regional centre or develop an existing one are as follows:
   ▶ a minimum of two new/additional (whole time equivalent) consultant allergists (for adult services) offering a multidisciplinary approach. This is the minimum requirement to provide necessary cover for diagnostic procedures and specialist treatment.
   ▶ a minimum of two full-time allergy nurse specialists
   ▶ one half-time adult dietitian and one half-time paediatric dietitian with specialist training in food allergy
   ▶ two consultants in paediatric allergy, supported by paediatric nurse specialists and dietitians with expertise in paediatric allergy
   ▶ facilities for training for two specialist registrars in allergy (in some centres).
The regional centres should:
- provide specialist expertise for adult and paediatric allergic disease throughout their Region (tertiary care), including allergic disorders recognised for regional commissioning
- manage allergic disease in the local population which cannot be dealt with in general practice (secondary care)
- act as an educational resource for the Region
- network with and facilitate local training in allergy for organ-based specialists and paediatricians
- support training at local level for GPs and nurses in the management of common allergies in primary care.

Trainees in allergy

In order to create new consultant posts, it is essential to increase the number of trainees in the specialty. There are now only five trainees nationally.

The lack of trainees is creating a planning blight, because NHS trusts wishing to create new consultant posts cannot readily find suitable applicants. The Department of Health and the Workforce Numbers Advisory Board must recognise the need and provide for more funded training posts in allergy. Despite the pressing case for an increase in specialist registrar numbers, and a provisional agreement for seven additional funded posts, allergy has been allocated no new funded posts for 2003–5.

Other consultant posts in allergy

In addition to regional allergy centres, further consultant allergist posts need to be created in other teaching hospitals and district general hospitals in each Region to deal with local needs. All teaching hospitals should have an allergy service provided by a consultant allergist. One model might be for a shared appointment between trusts. This should follow the establishment of regional centres.

Training in allergy for primary care

Primary care must ultimately provide the front line care for allergy but considerable development is needed.

The training of GPs and practice nurses in allergy needs to be improved. A key part of this will follow from interaction with consultant allergists, and the inclusion of clinical allergy training in the undergraduate medical curriculum. There are currently a number of allergy courses for GPs and practice nurses, eg through the National Respiratory Training Centre, Southampton University, or one-day training courses run by the BSACI. However, a much more comprehensive nationwide approach is needed, covering primary care training across the NHS. The development of general practitioners with a special interest (GPSIs) in allergy, trained in and linked to regional centres, should support this.
Organ-based specialists with an interest in allergy

Organ-based specialists will continue to contribute to allergy care and have primary responsibility for patients with asthma and eczema, in patients with single-organ involvement. They should network with the specialist allergist who can act as a resource in identifying/managing allergy. The increase in allergy means that greater awareness of the contribution of allergy in these organ-based specialties is important.

Summary

The NHS is currently not coping with the size and nature of the problems presented by allergy and related conditions. In order to develop a coherent model of service delivery, which would eventually be primary care based but networked to specialist allergists, major allergy centres must first be developed in all parts of the country. This requires the urgent creation of more consultant posts and training posts in allergy. These are key to:

- the improvement of patient care
- the prevention of severe and fatal allergic reactions
- the development of a coordinated allergy service
- understanding and containing the allergy ‘epidemic’.