



Meeting the challenges of the National Allergy Crisis

A report from the All Party Parliamentary Group for Allergy and the National Allergy Strategy Group



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Contents

Foreword by Jon Cruddas MP	3	The education gap	28
Executive summary and Recommendations ..	4	Key Recommendation	28
Background	12	The missing workforce	29
Sustainability and transformation	13	Example - the impact of drug allergy	30
The current situation	14	Increased prevalence	30
The impact of allergy	14	Poor access to specialist care	30
Hospital admissions	14	Cost to patients	30
The allergy epidemic and what it costs ...	14	Cost to the NHS related to misdiagnosis of a drug allergy	30
Prevalence rates	15	Immunotherapy	32
Allergy - a whole body disease	15	The provision of immunotherapy in the UK	32
Allergy and the NHS long term plan	17	Looking to the future	33
Prevention	17	Key Recommendation	33
Keeping people out of hospital	18	Commissioning	34
Health inequalities	18	Key Recommendation	35
Respiratory disease	19	The healthcare community	36
Covid	19	Health Visitors and Midwives	36
Summary	21	Pharmacists	36
Key Recommendation	22	Nurses	36
Lack of consultant allergists and trainees	23	Dietitians	37
Trainees in allergy (junior doctors entering specialist training to become allergists) - the facts	23	Back to training	37
New revision of the adult allergy training programme	23	Mind the gap	37
Consultants in allergy - the facts	24	Key Recommendation	38
Key Recommendation	24	Living with allergy	39
Primary care overview	25	Prescription charges	39
Most GPs have no training in allergy	25	How allergy impacts on everyday life	39
Allergy is included in the new 2019 GP curriculum	25	The essential role of patient organisations	41
Examples of the importance of allergy training for GPs	25	The four key patient requirements	41
What is needed?	27	Acknowledgements	42
Other ways of working	27	References	43
Key Recommendation	27		

Foreword



Jon Cruddas MP - Chair, All Party Parliamentary Group for Allergy

20 million people in the UK, a third of the population, are living with allergic disease with more than five million of these severe enough to require specialist care yet our allergy services remain inadequate, often hard to access and are failing those who need them the most.

In 2004 the House of Commons Health Select Committee found allergy services to be totally inadequate and made radical suggestions for change. Despite this and the many inquiries and reports that have followed, including the House of Lords Science and Technology Committee report in 2007, little has changed, and allergy remains an under resourced service within the NHS.

There is no evidence of a serious attempt to increase the number of allergy specialists in the NHS workforce nor of any co-ordinated effort to improve care provision in any other way, nationally. It is a worrying fact that there are only 11 allergy trainee posts in England despite the 2004 report recommending 40 and as a result only 2 will qualify each year. This is fewer than in Lithuania which has a population of three million.

Change is required and is now long overdue. For the growing number of people living with allergic disease in the UK, their condition can have a significant and negative impact on their lives. It is frightening and restrictive to live with a condition which could cause a severe or life-threatening reaction at any time.

This report has been produced collaboratively by the All Party Parliamentary Group for Allergy and the National Allergy Strategy Group which has been campaigning for nearly two decades to improve NHS allergy care and as a result the lives of the millions affected by allergic disease. The following would not have been possible without the joint working of the professionals, the patient organisations, and the patients themselves.

The time has come for the Government and the NHS to give allergy the priority it deserves and to recognise the true burden it can place on those who are affected and their families and wider communities. This report looks at the solutions to the problems and makes sensible, achievable recommendations for change. We look forward to seeing them implemented.

Executive Summary

1. The care for patients with allergy is inadequate. Change is needed now.

NASG has been making the case for improved allergy services for years, since the first Royal College report 'Allergy the unmet need' in 2003.¹ Recent high-profile cases of fatal anaphylaxis have brought shortcomings in NHS service provision and a lack of wider public understanding of allergy into sharp focus, specifically highlighted by coroners in their 'Prevention of Future Death' notices.² The coroner stated 'There is a risk that future deaths will occur unless action is taken'; and 'There appears to be a lack of awareness nationally of the simple but vital messages...'

2. Defining the problem

2.1 Allergy is a modern-day epidemic, neglected by the NHS. About 1 in 3 people, or >20 million in the UK, have an allergy related disorder. A significant amount of allergic disease is severe or complex so that one patient suffers several disorders, each triggered by different allergies. Fatal and near fatal reactions occur, due to foods, drugs and insect stings.

2.2 In 2003 the Royal College of Physicians (RCP) reported a great unmet need,¹ confirmed in the House of Commons Select Committee report highlighting the inadequacy of allergy services.³ That report was so scathing that the Department of Health (DH) conducted a review in 2006.^{4,5}

2.3 Despite this major burden of disease, allergy has largely been ignored by the NHS. Allergy is poorly managed across the NHS due to lack of training and lack of manpower with expertise. Allergy is a very small specialty, despite the large burden of disease for patients and the NHS. The core problem is the very small number of specialists with expertise in allergy: the lack of consultants in adult and paediatric allergy. GPs receive little or no training in allergy, yet millions of patients have significant allergic disease. The mismatch is huge. It is not widely understood that allergy is a complex specialty involving a large number of areas, diagnosis is not straightforward, and expertise is required.

2.4 The lack of equality in service provision, with uneven geographic spread of the small number of existing comprehensive services, means that many patients are **denied access to services or have poor quality of care.**

2.5 Children are commonly affected (~40% suffer allergy) yet care is inadequate. Each year new births add 43,000 cases of child allergy to the population in need, some of which will be serious. Yet specialist services delivered by trained paediatric allergists are available to only a minority of those with serious disease.

2.6 NHS digital data shows the rise in allergy continues.⁶ Hospital admissions due to allergy rose by 52.5% in 6 years, 2011/12-2017/18. Admissions with anaphylaxis rose 29%. Paediatric anaphylaxis admissions have also increased. Many more are treated in A&E without admission, despite NICE guidance advising otherwise. Other admissions are labelled as asthma rather than anaphylaxis, so do not appear in these figures.

2.7 The covid-19 pandemic highlighted a new need for allergists to support the vaccine rollout. A major new workload arose, investigating anaphylaxis and suspected allergic reactions to the covid-19 vaccines and providing advice on who could be vaccinated and which vaccine would be safe. This has been delivered by a small cadre of allergists, building on their drug allergy expertise. Without their pre-existing specialist knowledge this would not have been possible. UK allergist have been at the forefront of covid allergy research and were the first to identify a cause for anaphylaxis to the Pfizer/BioNTech covid-19 vaccine.^{7,8} The British Society for Allergy & Clinical Immunology (BSACI) set up a Covid Vaccine Advisory Group; and an allergy advisor for PHE and MHRA was appointed.

2.8 The NHS has only 11 posts in England for doctors to train in allergy (this compares with several hundred in larger specialities). **Of the medical specialties, allergy has the smallest number of trainees**, and has been overtaken by audio-vestibular medicine, previously the smallest, which now has 18. The output of doctors trained in allergy (ready to take up a consultant post) each year varies from zero to 2. There were none over a recent 2 year period.

2.9 The **tiny number of allergy trainees is a bottle neck, stifling growth of the speciality**, preventing consultant growth and the start of new services. It also impacts care at other levels (eg primary care, health visitors, secondary care), where there is a need for local support and advice from allergy specialists.

2.10 Shockingly, despite repeat submissions over 20 years to the workforce bodies responsible for trainee numbers, including the intervention of a Minister to the Centre for Workforce Intelligence, **very little increase has happened**. Meanwhile, despite the demand, other specialities with a less pressing case have expanded. The NHS/ Health Education England workforce system has failed to recognise the population allergy needs.

2.11 There are few consultants: approximately 40 adult allergists and a similar number of paediatric allergists, working in a small number of allergy centres. **Access to consultant allergists is inadequate**. The RCP estimated the need for about 200 adult allergists in 2003. There is a demand from Trusts for new consultant posts in Allergy, which cannot be met because there are few trained doctors to fill these. With no access to specialists, patients are not referred despite the need.

The care for patients with allergy is inadequate. Change is needed now.



2.12 Most general practitioners receive no training in clinical allergy either as medical students (partly due to a lack of allergists in medical schools) or in their specialist GP training. Following Royal College of General Practitioners /NASG initiatives, the RCGP have recently introduced allergy into the new GP curriculum. This is progress and will enable the GPs of the future to better support delivery of allergy care. However, it will take time to upskill primary care as existing GPs will have to acquire knowledge through courses and self-directed learning.

2.13 By contrast, UK is world leading in allergy research, where there has been investment locally. Major global achievements include for example the LEAP and EAT studies at Guy's & St Thomas' Hospitals and development of the first therapy for peanut allergy (peanut oral immunotherapy) and the TRACE studies from Cambridge.^{9,10,11,12} The many advances in immunotherapy from the Royal Brompton, Imperial, group are renowned.^{13,14} UK allergy guidelines (BSACI) are highly regarded internationally.¹⁵ Yet failure to invest in clinical services nationally means NHS provision is inconsistent and often poor, falling far below other developed countries in many areas.

2.14 The new training programme in allergy from August 2021 (part of specialty wide changes) will combine allergy with a different specialism, clinical immunology, which deals with rarer immunodeficiency diseases and which most doctors undertaking this training programme will never treat. This will dilute and downgrade the quality of allergy specialist training¹⁶ and **create significant redundancy in training**, just at a time where the need for full specialists in allergy is immense. However, it **could be an opportunity**, providing *i.* an allergy dominant programme was implemented and *ii.* posts were diverted to this programme rather than the other programme, Immunology, appropriate to meet the clinical needs of both types of patient. But these details are not yet agreed.

2.15 There is now a reduction in some allergy services, with closure or restriction of services mainly amongst secondary care providers, because they are overburdened. Some secondary care services (delivered by other specialities with limited allergy training) are sent patients with diseases out-with their experience, which creates risks for patient safety. Specialist centres have to reject GP referrals, with advice, because of long waiting lists. Given the lack of training in allergy in primary care, this is a no win situation for all, not least the patient.

2.16 The result of inadequate care is an enormous cost to the NHS, much of which could be avoided or reduced by better care. Allergy diagnosis means that the trigger can be identified, avoided and disease stopped: acute attacks are prevented; chronic disease is better controlled. As a result, cost is reduced because of fewer hospital admissions, A&E attendances, GP consultations and reduced drug use.

2.17 This problem has been known for nearly two decades and agreed in national expert Reports. Authoritative Reports since 2003, by the Royal College of Physicians, the House of Commons Health Committee, House of Lords Science and Technology Committee and the DH itself, all agree on the problem (that NHS provision for allergy at all levels across the NHS is inadequate) and the solutions (more training posts and consultants in specialist allergy and increased knowledge

of allergy in primary care).^{1,3,4,5} The need was confirmed in a 2010 joint report by the Royal Colleges of Physicians and Pathologists.¹⁷ Yet little progress has been made.

2.18 The consequences for **NHS patients** are: they face a post-code lottery; they are **hampered by wrong referrals and re-referrals; or get no referral**; they face denial of choice and of the benefits of improvements in allergy care; there is significant unmet need. To give one example, patients with suspected severe drug allergy are not investigated or are inadequately investigated putting them at risk of anaphylaxis. Others, without investigation, are prescribed expensive alternative drugs with side effects, lengthening hospital stay.

2.19 These issues and the resulting lack of effective allergy care need to be recognised and corrected by NHS England and Health Education England. **A national workforce plan and strategy for allergy is required.** Action is needed, not more Reports.

3. What previous National Reports found

In 2004 the Commons Health Committee said that a national allergy service within the NHS is urgently required and the Department of Health must begin to make changes without delay.

A series of Reports were produced, including:

- Allergy the unmet need, Royal College of Physicians, 2003 ¹
- The provision of allergy services, House of Commons Health Committee, 2004 ³
- A review of services for allergy, DH, 2006 ⁴
- The nature and extent of allergy in the UK, Evidence in DH report. British Society for Allergy & Clinical Immunology, 2006 ¹⁸
- Allergy, House of Lords Science and Technology Committee, 2007 ⁵
- Allergy Services: Still not meeting the unmet need. Royal College of Physicians and Royal College of Pathologists, 2010 ¹⁷

These reviewed the prevalence of allergic diseases, consequent patient need and service provision. **The findings and recommendations were similar across these Reports.**

Defined the problem - Large service need identified

Patient numbers / complexity / severity of disease were delineated. Allergy was poorly managed across NHS due to lack of training and lack of manpower with expertise. This was because i. there was a very small specialist service; and ii. GPs mostly did not receive allergy training in medical school or in their postgraduate specialist training.

The result was a gross imbalance between service provision and patient need.

Key recommendations - **Improve specialist services**

- Create more consultant allergist posts and create more allergy trainee posts.**
- In primary care, better awareness and knowledge of allergy.**



Examples of what was said:

DH: said we need 'a critical mass of specialist allergists' (2006)

The Commons Health Committee: recommended 'increase the number of allergy trainees (national training numbers) by +40 (starting with +10 in 2005; and +10 in 2006)'

Patient experience (from patients and the patient support groups) showed long waits to see a specialist; that GPs did not know where to refer; patients being referred to services without the appropriate expertise eg in drug allergy; little understanding of allergy; multiple GP appointments eg an average of 5 GP appointments until cow's milk allergy was suspected in babies.

4. Not enough progress 18 years on

Whilst there have been some advances eg NICE guidelines on allergy and care pathways for children with allergic disease (with Royal College of Paediatrics and Child Health, RCPCH), both recommended by DH, the main problems remain, little changed. There are too few consultant allergists, too few trainee doctors in allergy; and too little awareness of allergy in primary care. At all levels in NHS, there is a lack of workforce with the appropriate competencies (for disorders affecting one third of the population). Creating a cadre of specialists is the essential first step, and a pre-requisite to support GPs and other health care providers, to deliver allergy care across the NHS.

5. Aim of this Report

The aim is to enable change; a call to action, almost 2 decades on.

6. Recommendations for action

6.1 Investment in Allergy: a National Plan for Allergy

6.1.1 Make allergy a priority: implement a National Plan for Allergy.

This would require a strategic development process led by collaboration between DH, NHSE, HEE and workforce planners on the one hand and the NASG, BSACI, Allergy UK and the Anaphylaxis Campaign on the other, to develop a National Plan. After two decades of inaction, change must be implemented now. The Joint Royal College of Physicians Training Board (JRCPTB) and the Royal Colleges of Physicians, Paediatrics and Child Health, Pathologists and General Practice would have important roles on development and delivery of training programmes that meet the patient need.

Key to this is for many more trainee posts in allergy in the new adult allergy training scheme; and there is a perfect opportunity to achieve this by redistribution of posts to the allergy programme, aligned to patient need, combined with a real increase in numbers. Also to increase the number of trainees in paediatric allergy. And for national and local commissioners to recognise the need for allergy and promote it from the bottom of the pile of specialists, and assumptions that it can be done by other specialists. And for education across primary care, health visitors, dietitians and other health care professionals.



6.1.2 Establish an NHS England lead for allergy to oversee this.

We propose a National Clinical Director for Allergy or equivalent with authority, working with designated allergy civil servants, with a supporting structure.

Improvements will not be possible without 6.1.1 and 6.1.2. The lead for allergy will be accountable for the development and then delivery of a plan for specialist care and primary care.

6.2. Specialist Care

6.2.1 Create a major expansion of the specialist allergy workforce: this is essential to improve care.

6.2.2 The GMC and the Joint Royal College of Physicians Training Board (JRCPTB) to ensure a strong allergy dominant training is maintained in the planned new training programme Allergy (combining Allergy with Clinical Immunology, part of the Immunology training programme), so that the quality and quantity of Allergy training is not significantly reduced. Training centres must have the volume and expertise in all aspects of allergy. This is essential to ensure allergy specialists of the future are appropriately trained and can safely deliver care.

6.2.3 Allergy trainee numbers.

Health Education England to expand trainee numbers in allergy. Create a minimum of 40 additional training posts in Allergy (under the revised training also known as 'Allergy & Clinical Immunology'). This is a vital step. Rebalancing of trainee places is required between the old Allergy and Immunology programmes. The allocation of training posts has not previously responded to patient need in allergy. The new training plans offer an opportunity to redress this and increase trainee numbers in allergy.

6.2.4 Plan for a minimum of 4 consultant allergists (adult) + 2 paediatric allergists in every major teaching hospital; with additional hospitals with allergists in large conurbations or where geography means patients have to travel long distances to a teaching hospital.

6.3. Primary care

6.3.1 Ensure all GPs and designated primary care health care professionals have some allergy knowledge (1 in 3 patients in each practice have allergy related problems; 8% of GP consultations are for allergy).

6.3.2 Some of this is happening. The RCGP have added allergy to the new GP curriculum (2019) following on from the NASG/RCGP initiatives. This will support improvement in allergy awareness in the newly qualified GPs of the future.

6.3.3 Include allergy in GP trainees' exit examination (MRCGP) to ensure 6.3.2 is delivered.

6.3.4 Improve allergy education for the already qualified GPs (awareness of allergy courses; allergy to be a mandatory component of on-going professional development in appraisals).



6.3.5 GPs to have the competencies to achieve the following quality standards:

Recognise allergy symptoms

Know how to take a quick allergy history

Understand allergy tests and how to interpret them

Knowledge of adrenaline auto- injectors (AAIs)

Have allergy referral pathways adult & child; access to specialist and other providers of allergy services

Awareness of the NICE guidelines on allergy

Knowledge of the guidelines for cow's milk allergy or intolerance in infants

Knowledge of the BSACI primary care guidelines

6.3.6 Health Visitors and/or practice nurses – one responsible for allergy in each practice or consortium of practices; with some training.

Asthma nurses to become 'asthma and allergy' nurses

Asthma nurses to be aware of need for good control of asthma in patients with food and other allergies

Knowledge of AAIs and ability to train patients to use these

Health visitors to be aware of guidance on food allergy in infants and children

6.3.7 *Local commissioners* (CCGs) should understand the allergy needs of their population; and that it is not adequate to assume that other specialities can deliver specialist allergy care. Commissioners should ensure access to adult and paediatric allergy consultants and pathways of allergy care.**6.3.8** *National Commissioners* should ensure there are national agreements on commissioning eg for immunotherapy, drug allergy investigation etc.**7.****Summary**

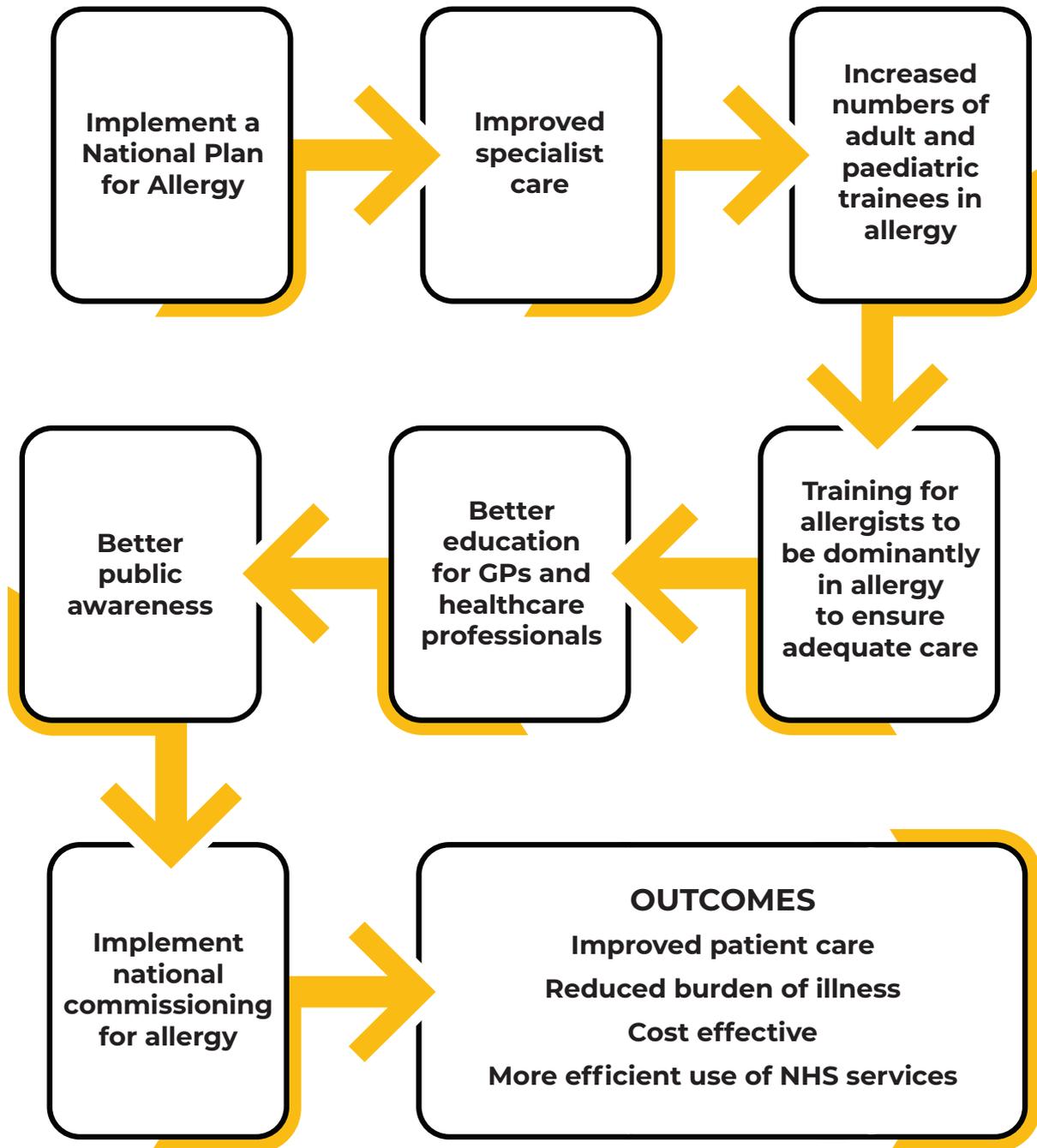
Supporting growth of the speciality of allergy would enable delivery of the much needed specialist care giving more patients access to an accurate diagnosis, which should surely be delivered by a modern NHS. Patient safety and the prevention of severe life-threatening reactions and control of chronic disease is paramount. More specialist allergists are also essential to support colleagues in primary and secondary care and improve integrated care, keeping more patients out of hospitals. This development would tackle the geographical inequalities and lack of access to specialist allergy services. Thus a relatively small investment would be an effective multiplier and deliver wider dividends. This model should result in better care for patients in line with the NHS long term plan.

Addendum

Another patient has died of anaphylaxis, this time from the agent PEG, which is a cause of drug induced anaphylaxis^{7,37} again with a 'Prevention of future deaths report'¹² by the coroner: <https://www.judiciary.uk> Ref 2021-0258



Summary - Key recommendations



Background

What is allergy?

Allergy is a 'hypersensitivity' reaction, or exaggerated sensitivity, to substances which are normally tolerated. Such substances are known as allergens. Examples of common allergens include peanuts, milk, shellfish, cats, medicines and grass pollens. These allergens trigger the production of a harmful antibody, immunoglobulin E (IgE). In an allergic reaction, the interaction between the IgE and the allergen causes the release of inflammatory chemicals such as histamines and leukotrienes. These cause symptoms such as sneezing, itches, rashes and falls in blood pressure; they may also cause airway narrowing, which leads to shortness of breath and wheezing, and swelling which, if in the mouth, throat or airway, causes severe difficulty in breathing. As well as causing reactions to foods, inhalants, medicines, vaccines, latex and insect stings, allergies are closely involved in a range of other diseases such as asthma, rhinitis and eczema.

In 2004, **the Commons Health Committee found allergy services totally inadequate and made radical suggestions for change.**

In 2004 the Commons Health Select Committee inquiry into NHS allergy services³ recommended that it was necessary to:

- Train 40 new specialist doctors – 20 for adult and 20 for paediatrics. Once trained it was envisaged that these doctors would join the allergists already at work in the NHS to become the core of a modern NHS allergy service which would be available to patients across the UK.
- Create a minimum of 40 allergy consultant posts for these qualified specialists to move into once they are trained. It was hoped good doctors would be attracted into the specialty as a result.
- Have a major specialist centre, in adult and paediatric allergy, for each area of the country. This was recommended as a "key step" as it would provide the whole NHS with the expertise and infrastructure to support other developments in allergy care.
- Publish and put into practice an "action plan" to bring allergy into the mainstream of the NHS.

The lack of trainee posts in allergy is the block to the growth of allergy services

In the longer term the report concluded that the scale of need for allergy care would require the national allergy service to ensure that:

- All healthcare professionals working in primary care have appropriate exposure to the diagnosis and management of allergy as part of their clinical training.
 - All primary care providers have a named person with responsibility for allergy.
-

- All Primary Care Trusts have a team of healthcare professionals with a special interest in allergy who are available to help and advise on allergy case diagnosis and management.
- All teaching hospitals have a specialist allergy clinic run by consultants in allergy which would be a resource both for patients and for training and research.
- Regional specialist centres act as centres of excellence, managing the more complex cases of allergy and supporting the regional network of allergy care.

However, despite these recommendations and numerous other reports, inquiries and national reviews, including the House of Lords Science and Technology Report of 2007,⁵ there is no evidence of a serious attempt to increase the number of allergy specialists in the NHS workforce nor of any co-ordinated effort to improve care provision in any other way, nationally. There has been some growth but there are only a small number of consultants in allergy - only around 40 offering a specialist service in adult allergy. Many Trusts want to appoint consultant allergists but the block to expansion is the lack of doctors trained in allergy to apply for these posts.

In evidence to the DH Review of NHS allergy services (2006)⁴, BSACI suggested how the 20 million of the population with allergy-related disease could be managed.

- At least 5 million require specialist referral
- A further 5 million could be managed in primary care, only if primary care was skilled up in allergy
- About ten million could be self-treated or managed in primary care, without formal allergy diagnosis.

These numbers have increased since 2006.

There are only 11 trainee posts in total in England. 40 additional posts were recommended in 2004 ... No change occurred

Sustainability and transformation not achieved

Had action been taken after the national reports over a decade ago, allergy care would already have been transformed. Instead existing services are being cut because of the lack of a supply of doctors trained in allergy.

If the NHS had created more training places in allergy (as recommended by the Commons Health Committee in 2004)³ and encouraged trusts and commissioners to require fully trained allergists, allergy care would have been transformed from the patch work post code lottery and highly variable quality of care standards that still exist¹⁷ years later. Because of local efforts, facilitated by the introduction of re-imburement of NHS Trusts on a 'Payment by Results' basis, new NHS consultant allergist posts have been created. 16 new posts have been established in the last decade albeit mostly in established allergy centres. Whilst this will have certainly benefited people living with allergy in those local areas, it is of minor impact in the national context. Importantly, Trusts seeking trained allergists are unable to find applicants, as each of the tiny number of trainees is snapped up on completing training. Several services have closed or reduced activity.

The Current Situation

Disorders where allergy may be involved affect one in three of the UK population which equates to more than 20 million people. Despite full speciality status, there are few trained allergists in the UK and across the NHS workforce, knowledge of allergy is poor.^{1,3,19} However, allergy is a significant and well established speciality in developed countries around the world.

**20 million people
in UK have an
allergy related
disorder**

The impact of allergy

For the growing number of people living with allergic disease in the UK, their condition can have a significant and negative impact on their lives. It is frightening and restrictive to live with a condition which could cause a severe or life-threatening reaction at any time. In particular, parents of children with allergic disease live in fear of their child having an allergic reaction when they are out of the home, where the understanding of their condition may be poor or confused. Allergies are the most common chronic disorder in children. 6-8% of children up to the age of three years have a food allergy. Drug allergy not only creates risk of severe reactions, but places restrictions on which drugs can be used, with negative impact on health. Yet many patients do not have access to a doctor trained in drug allergy and their allergy remains undiagnosed or wrongly attributed. Allergy also has other impacts including loss of school days and educational attainment, economic impact through loss of working days, health and social disadvantage, financial burdens on both individuals (and the health services) and, at the most extreme, loss of life.

Hospital admissions

It is estimated that one in 1,333 of the population in England has experienced anaphylaxis (this is a severe sudden onset and potentially life threatening reaction) at some point in their lives. Hospital admissions for a severe allergic reaction increased sevenfold in the ten years from 1990 to 2000; from 2002 to 2012 there was a doubling of admissions with anaphylaxis due to food allergy alone^{20,21,22,23} and from 2011-17 admissions with allergy increased by 52%, and with anaphylaxis by 29%.⁶

The allergy epidemic and what it costs

One in four adults and about one in eight children in the UK has allergic rhinitis which equates to around 16 million people.²⁴

These people are four times more likely to suffer from other related conditions which are driven by allergy, such as asthma, eczema and food allergy. However, allergic rhinitis, which includes hay fever, animal and house dust mite allergy, remains poorly managed and under recognised as an allergy. The percentage of people diagnosed with allergic rhinitis, asthma and eczema has trebled over the past 4 decades.¹

Drug allergy, for example to antibiotics, pain killers or drugs used in general anaesthesia, is a growing problem and can make safe prescribing difficult. A drug allergy diagnosis requires expertise and knowledge to which many patients will have no access and yet if the drug is one that is given by injection, re-administration can cause fatal anaphylaxis. There is also cost to patients' health if a suspected diagnosis of penicillin allergy results in expensive alternative antibiotics with more side effects being used. Up to 90% of those diagnosed with penicillin allergy do not actually have the allergy hence there is a crucial role for more accurate diagnosis.

Allergic disease is widespread and often complex. Of the 20 million people with allergic disease, about 10 million could be dealt with in primary care and at least 5 million people have sufficiently severe symptoms to require specialist care. However, patients could be managed better in primary care if knowledge and understanding of dealing with allergy in primary care was more robust.

Allergic disorders cause substantial costs for the NHS. There is a lack of data on overall cost of allergy in the NHS. There was an estimate of £1 billion for allergy related illness in 2004. Since then anaphylaxis and related admissions have increased by 200-300%, admissions due to allergy overall have increased, primary care visits for allergy have increased to 8% of their total consultations, and the complexity and severity of allergy has increased as well as the number of patients affected.

Prevalence rates

Prevalence rates in the UK are among the highest in the world; 40% of children in the UK have been diagnosed with allergy³ with each birth cohort increasing the numbers of people needing help; the epidemic continues to grow, increasing the burden on the NHS and making allergy a particular and significant problem for today's children, and their families, and, crucially, for tomorrow's adults. Anyone can be affected and patients from Black, Asian and minority ethnic backgrounds are at particular risk²⁵ demonstrating poorer outcomes from allergic disease.

**Anaphylaxis
admissions up
29% and allergic
admissions up
52% in 6 years**

Allergy – a whole body disease affecting multiple systems

Allergy is a 'hypersensitivity' reaction, or exaggerated sensitivity, to substances which are normally tolerated (allergens) for example, foods including peanuts and milk; animals; house dust mites; medicines; insect stings and pollens. In allergy, an unwanted and harmful antibody (called IgE) is produced in response to an allergen. When the body is exposed to the allergen (the allergy trigger), this interacts with the specific IgE antibody, leading to the allergic reaction.

Allergy services also deal with non-IgE mediated disorders. In some conditions – for example food intolerance, angioedema, anaphylaxis, rhinitis or drug allergy - the same symptoms occur in other ways, and the IgE antibody is not involved. These non IgE-mediated reactions present people with challenging health problems which can be more challenging to diagnose and are an important part of allergy practice. Idiopathic (non-allergic) anaphylaxis accounts for about a quarter of the cases of anaphylaxis.

Allergy is a whole-body disease. It can affect many organ systems at the same time (rashes, breathing difficulties, collapse, or vomiting and abdominal pain), or the way it expresses itself may be isolated to one part of the body. For example, allergic asthma affects the airway and eczema affects the skin. In food allergy it usually affects several parts of the body.

Allergy commonly causes several different diseases in a single patient, for example hay fever affecting the nose and eyes due to pollen allergy, allergic asthma, year-long allergic rhinitis due to house dust mite allergy and anaphylaxis due to foods. These patients have a 'package' of allergic disorders. Certain fruits are now commonly causing allergic reactions and these patients usually have co-existing allergic rhinitis, and sometimes asthma due to pollen allergy. This is termed Pollen-Food syndrome and illustrates the complexity of allergic disease and its potential for life changing consequences.

When complex causes result in severe reactions or several disorders, an accurate allergy diagnosis which identifies an approach to management is crucial for the effective treatment and holistic care of a patient. An accurate diagnosis identifies the trigger, informs strict avoidance and minimises risk, preventing, or reducing further symptoms, and optimizing the patient's quality of life. However, for many patients, the lack of allergy services can mean that allergy is not considered in a diagnosis and the symptoms are treated with drugs, but the underlying cause and the need for avoidance may not be identified. Therefore, the opportunity to manage the disease is missed, and symptoms continue.

Conversely, the specialist allergist can exclude allergy when a patient has been wrongly diagnosed. An example of this is penicillin allergy where the removal of an incorrect 'label' of penicillin means expensive alternative antibiotics are no longer required. These alternative antibiotics, as well as being costly, have hidden additional cost as they cause more serious side effects and lead to prolonged hospital stays. An allergist also has an important role in excluding food allergy which is often wrongly diagnosed on the basis of a positive test by itself.

Identifying a food or a drug allergy allows the trigger to be avoided. This prevents attacks, saves lives, saves money

Advances in our understanding of allergic diseases has also resulted in the development of new treatments. These include the use of biologics which can be highly effective in the management of eczema, asthma and urticaria as well as more effective desensitisation treatment not only for respiratory allergy but also for food allergies. Palforzia became the first FDA approved treatment for food allergy in the US in 2020 and others are in development, likely to revolutionise the management of peanut allergy. However, such new approaches need specialist expertise to ensure the right patients receive them in a safe and effective manner. To deal with this burden of disease and transform the serious deficiencies in care, a cadre of full allergy specialists, adult and paediatric, is required. This can then uplift and support care at many other levels across the NHS, but particularly primary care.

40% of children and 30% of adults have one or more atopic disorders

Allergy & the NHS long term plan

Better allergy care, as proposed in this Report, would meet the objectives of the NHS long term plan. The very small specialist workforce, the lack of awareness of allergy in primary care and the resulting referrals to other specialities that have limited or no expertise in the problem means that patients are bounced around the NHS system with repeated GP appointments or inappropriate hospital referrals, wasting time, money and resources.

Children are most affected, over 40% now having allergies. For example, it takes an average of five GP visits before cow's milk allergy is diagnosed in infants;^{26,27} and children with food allergy are sent to hospital clinics not able to deal with them.

Prevention

If an allergy to a food or a drug is identified, avoidance can prevent further acute episodes. The consequence of an accurate allergy diagnosis and good management is the prevention of further episodes. For example, specialist care for patients with a nut allergy can prevent further reactions, keeping people out of hospital and saving NHS resources. Local anaesthetic allergy is often suspected but is only rarely present. Confirming this and removing the 'allergy label' means that these patients no longer need general anaesthetic for minor surgery or dental extraction, reducing costs and resources and hugely benefiting the patient. Immunotherapy not only controls severe disease but can also prevent the development of other allergies and asthma in children, but it is only available to a minority of those eligible.

Because of the lack of allergy expertise, patients are bounced around the NHS system wasting time, money and resources

The UK has a tiny specialty of allergy for a huge disease burden - NHS trains fewer doctors in allergy than in audio-vestibular medicine

Recent research, led by British researchers, have impacted on public health guidelines internationally, demonstrating that early introduction of potentially allergenic foods such as peanut, into the infant weaning diet, can reduce the risk of potentially lifelong allergy developing. However, these findings need to be implemented on a national scale to help maximise the benefits of reduced allergy prevalence. Specialist centres have set up focussed clinics, identifying those children at highest risk of developing allergies and actively managing their diet to reduce the prevalence of future allergy but such approaches require widespread adoption for local delivery which in turn needs local specialist leadership, which is currently not available.

Keeping people out of hospital

Specialist care keeps patients out of hospital and in most allergy centres the aim is to achieve this objective for most patients in a single visit. By increasing the specialist workforce and including allergy in primary care training, developing integrated care, more patients could be managed in primary care with a large number quickly returned from the specialist to the GP for ongoing care or self-care.^{18,32}

Health inequalities

England can boast some of the world's pre-eminent specialist clinical and research centres in Allergy and alongside an impressive academic output. There are also 2 hospitals (Southampton General & Guy's & St Thomas') which have been accredited as World Allergy Organisation Centres

Allergy care is a post-code lottery. There is major geographic variation in access to services. Most are in London and the South East. Patients near the specialist allergy centres get world class care but for the majority, care is inadequate.

of Excellence. This award requires the centre to evidence that they actively intensify and accelerate multidisciplinary scientific and clinical innovation, education, and advocacy worldwide providing excellence in education, research, training to various stakeholders in allergy, asthma and clinical immunology. This demonstrates that where the investment is made, UK allergy centres will contribute at local, national and international level. However, there is a significant inconsistency in provision of allergy services, which has a direct impact of the communities around them. Our current system has been described as creating first and second class 'allergy citizens', where a child born locally to a renowned specialist centre will have access to cutting edge translational research (along with the consequent clinical benefits) whilst another will not have access to even basic specialist services. Other factors such as ethnicity can also impact here, with strong evidence that patients from minority ethnic backgrounds having less access to specialist care and poorer allergy related outcomes.^{25,33}

Specialist allergy services are very limited outside of the South East with the North and West the most deprived in this respect. Patient organisations' data shows that patients face long journeys or, at worst, cannot access the appropriate specialist service at all. Or referral is made to a service without the appropriate expertise. These patients

go round in circles in the NHS. However, patients living near to London, where there are more services, also report difficulty being referred, as seen in this quote from a mother of a child with food allergy speaking to the All Party Parliamentary Group on Allergy:

"Despite living in the South East of England I have struggled to access care for my son in numerous different places and we have had to be re-referred many times as a result."



Respiratory disease

Allergy in the nose (allergic rhinitis) affects 10-15% of children and 26% of adults in the UK.^{24,34} Asthma is also common and much of the asthma seen in young people is driven by allergy triggers. Allergy was identified as the second most common trigger, after respiratory infection, as a cause for asthma deaths.^{35,36} Yet allergy is rarely considered as a trigger for asthma. Identification of triggers leads to improved asthma control and fewer attacks. One example is allergy to the mould *Alternaria* released into the air at harvest time triggering asthma and leading to hospital admissions. Recognising the allergy, prescribing inhalers at the right time, can prevent these attacks. But without allergy knowledge, the emergency admissions at the same time of each year go unnoticed and keep happening.

Identifying and managing allergies could prevent these severe attacks and reduce demand on emergency departments and intensive care facilities. However, in too few people is allergy considered as a factor in their asthma and this is predominantly due to a widespread lack of awareness of allergy across the NHS workforce. One or two consultations with a specialist allergist is usually all that is needed, with follow up in primary care and good self and family awareness of how to manage the allergy trigger.

Impact of COVID-19

In December 2019, a novel coronavirus (SARS-CoV-2) emerged in China and subsequently spread globally, with a pandemic of the disease (COVID-19) being declared by the World Health Organization in March 2020. The first confirmed cases in the UK were reported in January 2020, and over the next few months, restrictions were placed on individuals and businesses to limit spread of the virus. In anticipation of major demand for hospital wards and equipment to care for patients with COVID-19, most elective activity was cancelled or deferred and staff redeployed, which had a significant impact on provision of specialist allergy and immunology services across the UK. Many were left with few staff and limited resources, trying to maximize the care provided in difficult circumstances, rapidly prioritizing certain patient groups, and reconfiguring their service models, with the leadership of the Royal Colleges and BSACI. Whilst there was some recovery of services between May and December, services were again hit by the rising tide of the second major peak of COVID-19.

The critical importance of having highly specialist allergy services was brought into sharp focus in December 2020, when there were 2 severe allergic reactions to the Pfizer/BioNTech COVID-19 vaccine in the first 24 hours of the national vaccine programme. No such reactions had been seen in the extensive Phase 3 clinical trials. Expert allergists were able to work closely with the MHRA

UK is a world class leader in allergy research and has centres of clinical excellence. Important contributions include the development of early weaning strategies to reduce the risk of food allergy and desensitisation treatments to help reduce the risk of reactions.

and Public Health England to support the ongoing decision making as to who should and should not receive the vaccine. As a consequence, the vaccine programme was continued and public confidence in the programme maintained.

At the time of writing 90% of people aged 16 and over have received a covid-19 vaccination with over 93 million doses of covid vaccine administered in UK. Although allergy to the vaccine is rare, hundreds of people have had anaphylaxis after the vaccine, and thousands require specialist allergy expertise to enable vaccination and make us all safer.

The Covid-19 vaccination programme has placed a major new demand on allergy services as all vaccine recipients face routine questions relating to their allergy status to understand whether they are suitable for vaccination and which vaccine they may safely have because of a background of allergy. This is a major problem because allergies have usually not been fully investigated because services are lacking. Covid-19 vaccination has brought these allergies out of the woodwork revealing the hidden burden of allergic disease (as set out in 'Allergy the unmet need' 2003 Royal College of Physicians and 'Allergy services: Still not meeting the unmet need' 2010^{1,17}); and where severe anaphylactic reactions have occurred to the Covid-19 vaccine, for diagnosis of the cause and suitability for a second dose. This might involve allergy diagnostic tests to agents where there is little or no experience and which are confined to highly specialist units because of the high risk of inducing anaphylaxis; and sometimes, may involve administration of vaccine.

Underpinning this there has been a need to develop a completely new knowledge base very quickly. This could only come from those with expertise in drug allergy. UK allergists had a world first, through research identifying a cause of severe anaphylaxis to the Pfizer Covid-19 vaccine (this is an excipient in the vaccine called polyethylene glycol (PEG), also known as macrogol).⁷ They also produced a guide to identifying 'at risk' patients, where certain Covid-19 vaccines may have to be avoided. This was only possible because of previous research by this group which led to development of a regime to investigate allergy to PEG and define a typical profile of such patients.³⁷ PEG is in the two mRNA vaccines currently available in UK, Pfizer and Moderna. (Link to study: <https://onlinelibrary.wiley.com/doi/10.1111/cea.13874>.)

The BSACI set up a Vaccine Advisory Group (VAG), which produced various documents to assist allergists in giving advice to GPs and for specialist centres investigating patients. This is being disseminated to allergists across the UK via the BSACI Allergy Update. An allergist advisor to PHE and NHSE has worked with the BSACI VAG. The patient groups, Allergy UK and the Anaphylaxis Campaign, working with the BSACI VAG, produced extensive advice and FAQs for patients and the public on their websites. This has been enormously valuable, again filling in for the gaps in allergy services.

The demand on allergy services because of Covid-19 vaccine is huge, accounting for up to a 50% increase in Advice and Guidance requests from GPs to allergists and a smaller increase in Referrals. This is hardly surprising given that 93 million doses of Covid-19 vaccine have been administered in UK. Many of these cases are complex and require expertise in drug allergy, an area of allergy which is available only in limited centres. This new problem yet again shows why many more than the current handful of doctors should be trained in allergy - we lack preparedness in allergy.

As the peaks of the pandemic have passed, staffing and facilities have recovered but the necessary changes to hospital processes that have emerged, such as the need for social distancing, have



markedly impacted the manner in which the service is provided and the capacity of the services, which were already inadequate. Consequently, access to specialist has worsened and waiting lists lengthened. This has had a particular impact on infants at high risk of food allergy. Early specialist assessment of this group, supported by testing, can allow for early targeted allergen introduction which reduces the risk of food allergy developing. Without this support, many children will develop what will be life long and potentially life-threatening food allergies.

The vast majority of consultations by allergy services since April 2020 have taken place via telemedicine (telephone or video consultations). The feasibility of telemedicine for some allergic conditions is challenging but it is likely to be the default means of consultation for the foreseeable future. Whilst there are important benefits to telemedicine: reduced travel time and cost for patients, improved access for patients unable to travel, and a reduced carbon footprint there are key disadvantages too. These include the inability to perform physical examinations or in vivo allergy skin testing. There are further challenges around safeguarding vulnerable patients, and potential inequity for patients unable to use some technology. The challenge for services is to find the right balance for each patient but in small services, with few specialists, there is little capacity for this.

Whilst there are opportunities for services to undertake more home-based procedures, many procedures performed by specialist services (eg venom and subcutaneous aeroallergen immunotherapy as well as many food and drug provocation challenges) need to be done within a supervised day-case unit with appropriate emergency facilities.

In the context of an inevitably more financially restrained healthcare economy, there are massive challenges ahead. Allergy services have historically not been prioritized in such times. A wholesale move away from tariff-based reimbursement schemes in the NHS, which have allowed for significant growth in high-volume, high-demand specialities such as allergy, to block contracts, removes the incentive for such growth and is a major threat to service development. This additional challenge to capacity comes just as the paradigms for treating one of the most common and dangerous allergies – peanut allergy, are starting to change. In the US, Palforzia become the first FDA licenced product to treat peanut allergy. However, this treatment requires multiple carefully supervised in-patient visits which will be very challenging to complete with current service capacity, meaning that UK patients will have little access to this new generation of treatments. There has never been a time when lobbying at local and national level for allergy and immunology services has been more necessary yet with so few specialist services there are too few specialists with too little time to do this effectively and allergy services risk being left further behind.

Summary

The NHS does not work well for allergy patients; it does not make access to diagnosis and treatments either easy or timely and, crucially, it does not help people to get and stay well. COVID-19 has further compromised accessibility to services.

**The NHS does
not work well for
allergy patients**

A small investment in increasing the number of allergy trainees and hence full allergy specialists will have a multiplying effect across the NHS and allow integrated care

However, for a relatively small investment, substantial benefits for both patients and the health service itself could be achieved and the changes resulting from the pandemic, such as virtual consulting, can be built upon. With the development of the proposed robust integrated care system, more patients would be managed outside hospital. It is 18 years since our first report and in the contexts of increasing numbers and the implications of more children developing allergic disease then the case for making allergy a clinical priority is compelling.

Key Recommendation

Create more training posts in allergy. Train many more doctors to be allergy specialists.

Increase the number of adult and paediatric consultant allergists (full specialists).

Increase allergy knowledge in primary care through training and education.

Bring allergy care into the 21st century, raise standards and the consistency of care across the UK.

Lack of Consultant Allergists and Trainees

The fundamental problem is a gross lack of consultants and only 11 trainee posts in adult allergy in the UK, with fewer still in paediatric allergy. This is the major factor limiting the growth of this much needed speciality. Despite the number of people living with allergy, poor care and uncontrolled disease is consuming NHS resources and impacting on lives. Astonishingly, allergy is the smallest medical speciality. There is a huge and evident imbalance between patient need and the provision of allergy services and it is time that allergy is identified as a priority need by NHS England and Health Education England.

Trainees in allergy (junior doctors entering specialist training to become allergists) – the facts

- There are just 11 places in England for doctors to train in allergy in comparison with the several hundred in the larger specialities
- The allergy curriculum is extensive, and the current training programme takes five (now to be reduced to 4) years
- At most, just two doctors trained in allergy complete their training each year, and in some years there are none
- Every allergy trainee who has come through training has been appointed to a consultant allergist post. These contrasts with some other specialties, where there can be an excess of trainees over the availability of consultant posts.
- For two decades, the argument for more training posts in allergy has been made to the various bodies responsible for Workforce (most recently Health Education England). Only once were four additional posts allocated, to be phased in, but the second two were then removed before they were realised.

Proposed revision of the adult allergy training programme

- New training programmes (as part of 'Shape of Training') for adult specialities are being introduced across all specialities which will reduce training to 4 years. Discussions on revising the separate Allergy and Immunology training programmes, each 5 years long, have been held.
 - Allergy and Immunology/Immunodeficiency are different specialisms with little overlap. Allergy is a high-volume clinical specialty with large unmet need. Immunodeficiency deals with rare diseases where there are strong links to the laboratory. There are 3,500 patients with primary immunodeficiency and others with secondary immunodeficiency but around 20 million with allergy. However some immunologists deliver allergy services. While other immunologists do only Immunology exclusively delivering specialist immunodeficiency services and diagnostic laboratory services.
-

- Allergy has huge demand and few trainees. Immunology has many more trainees.
- The plan is to combine Allergy training with Clinical Immunology (in practice this means immunodeficiency, the clinical part of Immunology), while retaining a separate full Immunology training. This risks diluting and weakening allergy training. This new programme is to be called Allergy (aka Allergy & Clinical Immunology). The separate Immunology training programme will provide a diagnostic immunology laboratory service and produce the full specialists in immunodeficiency.
- To meet the needs of patients, allergy training should comprise most of the new Allergy programme. Otherwise there will be redundant training as most doctors undertaking this new programme will practice only in allergy. Allergy training should be delivered by centres with the appropriate allergy expertise, to ensure sufficient quality.
- The number of training posts in these two specialties will be combined. The allocation of trainee numbers should take account of clinical need. Allocation of the majority of the training places would appropriately be to Allergy & Clinical Immunology so that training is directed to the unfulfilled patient need, whilst ensuring that both immunology and allergy needs are met. The size of the pool should increase.
- Shape of Training, provided it is used appropriately (ie a training programme dominant in Allergy is agreed and allocated the majority of the training posts), offers an opportunity to deliver the needs of Immunology and Allergy and at the same time increase the number of allergy trainee posts.

Consultants in allergy – the facts

- There are about 40 adult allergists and slightly fewer paediatric allergists.
- At present there is one adult allergist per population of 1.3 million.
- The population requiring specialist allergy care was calculated as at least 5 million (DH review of allergy services 2006, evidence paper submitted by BSACI 'Nature and Extent of Allergy in the UK^{4,18}). This was assuming primary care would be 'skilled up' to deal with much more allergy (an additional 5 million patients). Since these figures the demand for allergy services has increased.
- The Royal College of Physicians recommended that about 200 consultant adult allergists were required (Consultant Physicians Working for Patients, 2003 ¹).

Eighteen years ago the short term objective was for an absolute minimum of two consultant allergists (adult) and two paediatric allergists in every teaching hospital, as well as additional consultants in areas where there are long distances between teaching hospitals or large populations. This objective remains unfulfilled.

Key Recommendation

Train additional allergy specialists to support the millions of people requiring specialist care.

A large increase in the number of training places in both adult and paediatric allergy is needed now.

Primary care overview

Most GPs begin their practice career with no training in allergy. Yet they are frequently faced with allergic conditions in their day to day consultations. More than 1 in 3 of a GP's patients have allergy and 8% of their consultations are for allergy related issues.

Most GPs have no training in allergy.

Most GPs start in practice with no training in allergy. Those who are interested acquire their knowledge through self-learning on-line, or by attending short courses (if they are available locally). Few medical students gain any clinical allergy training in medical school so it is possible for GPs to complete their training with little understanding or knowledge of allergy. NASG, working with the Royal College of General Practitioners (RCGP), produced a Joint Report making proposals for a solution in 2006³⁸. NASG re-engaged with the RCGP in 2017-8 making the case for Allergy and suggesting ways of integrating allergy into the curriculum and proposing its inclusion in the GPs specialty examination, MRCGP.

Allergy is included in the new 2019 GP curriculum

Allergy has now been added to the 2019 revision of the GP training curriculum. This will have major benefits. What will be important to ensure Allergy learning is undertaken, is that allergy becomes embedded in the MRCGP examination.

This means that the GPs of the future will have improved knowledge of allergy. The established GPs will have to rely on self-directed learning, but many online courses and short courses are available.

Examples of the importance of allergy training for GPs

Following the DH review of allergy services in 2006 new NICE guidelines were commissioned leading to the publication in 2011 of Clinical Guideline, Food allergy in under 19s; assessment and diagnosis²¹. Later that year NICE published a second allergy guideline, Anaphylaxis: assessment and referral after emergency treatment.²²

Nevertheless, the guidance on food allergy is infrequently referred to or implemented. It seems that healthcare professionals working in primary care, including GPs, are unaware of this guidance. The NICE Anaphylaxis guidelines also include important messages for those in primary care.

In 2016 NICE published Quality Standard (QS) 118 on food allergy and QS119 on anaphylaxis (<https://www.nice.org.uk/guidance/published?type=qs>).

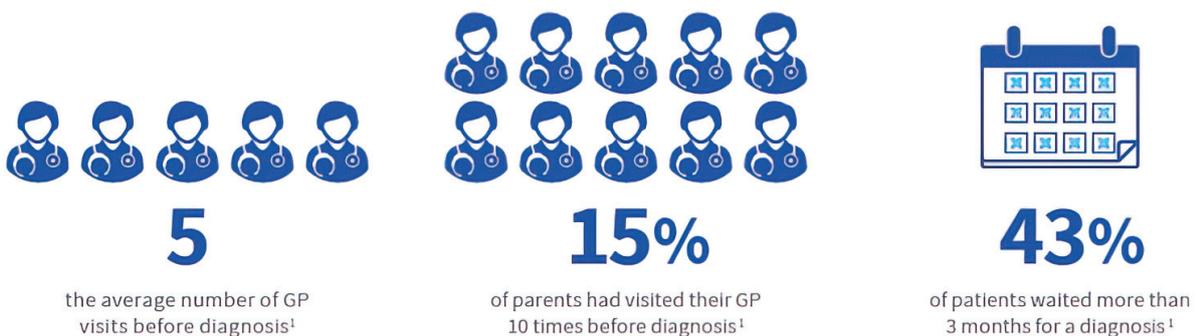
**Allergy training
has been included
in the 2019
revision of the
curriculum for
doctors training
to be GPs**

If primary care practitioners implement these standards of care quality of life will improve for those with allergies; the burden on accident and emergency departments from those presenting with avoidable reactions will be reduced and referrals to secondary and tertiary care will be appropriate.

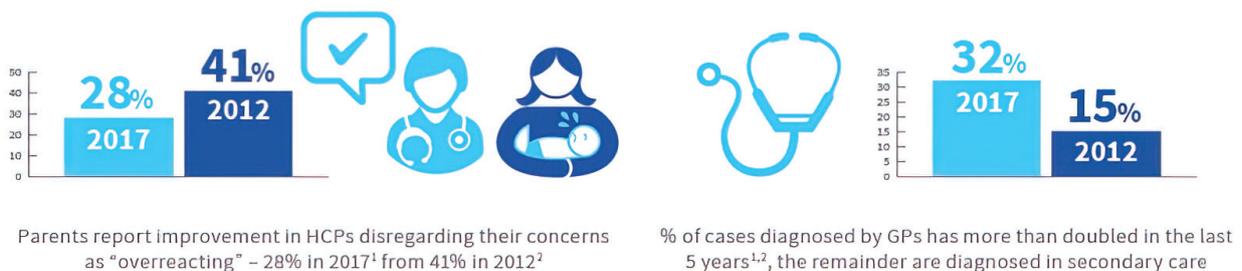
One example of the impact of lack of GP training is in cows' milk allergy in babies. On average five GP visits take place before adequate assessment and the start of the appropriate management pathway. In 41% of babies it took between 3 and 12 months to reach the diagnosis. Meanwhile, babies suffer and families are burdened with anxiety and distress.

The largest online survey of parents of children with Cows' Milk Allergy (CMA) in the UK confirmed that there has been little improvement in the time it takes to get a diagnosis in the last five years.^{26,27}

Continuing delays in diagnosing CMA



Improved confidence in HCPs



(Sources: 1 Allergy UK survey of 2,852 parents of children diagnosed with CMA conducted in July 2017. Data on file. 2 Allergy UK survey of 328 parents of children diagnosed with CMA conducted in May 2012. Data on file.)

Another example of this can be taken from Anaphylaxis Campaign's patient survey on the quality of allergy care in the UK. Of the 1217 respondents, 655 were parents or carers responding on behalf of a child up to 16 years old who is at risk of anaphylaxis. A minority of patients are advised on allergy avoidance when presenting to a general practise (23%) and an even smaller proportion are informed about the support services available (13%). Only 64% of patients presenting to a GP with suspected anaphylaxis (a severe reaction) are referred to an allergy clinic.³⁹

What is needed?

All these factors are closely connected, and in order to manage patients with allergy, improved education in primary care is required and the following are essential:

- The taking of an allergy focused clinical history. This is the cornerstone of diagnosis. To do this effectively, and given the time constraints in primary care, GPs must have some knowledge of allergy.
- It is essential for the GP to have knowledge of the allergy blood tests available, when to use them and how they are to be interpreted. A major source of diagnostic error is misinterpretation of results.
- Knowledge of the referral pathways for specialist care, what services are available locally and NICE guidance.
- Knowledge of adrenaline auto-injectors, their place in the management of allergies and importance of training in their use.
- Knowledge of the patient support organisations, such as the Anaphylaxis Campaign and Allergy UK, and the services and information they provide.

Because allergy is a major component of a GPs' work, allergy should be included in the GP examination

GPs are under huge pressure, but small changes in allergy knowledge will help.

Other ways of working

In many areas of the UK there is limited access to secondary and tertiary allergy centres. However, innovative support projects such as "*Itchy Sneezy Wheezy*" led by Imperial College Healthcare, London, working with a local primary care clinic, produced integrated respiratory and allergy pathways to improve the management of allergy in children. This project has allowed patients to be more rapidly diagnosed and managed in the community, together with a pathway showing who should be referred.

The *Itchy Sneezy Wheezy* project resulted in: ⁴⁰

- 22% reduction in unscheduled care
- 13% reduction in A&E attendance with respiratory and allergic conditions
- Increased professional confidence
- High levels of parent satisfaction

This project demonstrates that allergists working with their primary care colleagues can support a model of care where more patients can be managed outside hospital.

Key Recommendation

Educate primary care health professionals in allergy.

The education gap

Most doctors in the UK complete medical school training without any formal learning in allergy. Creating more consultants in allergy is a first step to ensuring some clinical training in allergy for medical students and, consequently, all those who eventually become GPs.

As a direct result of the lack of consultants in allergy, few medical students receive any clinical training in allergy. They receive a lecture on the mechanism of allergy and may attend a lecture on anaphylaxis, but clinical allergy is either poorly taught or not taught at all.

While there is an assumption that relevant training may be delivered in organ based subjects (respiratory, immunology, dermatology etc) this does not, in practice, usually cover the specific allergy content related to these disciplines. Even in medical schools with allergists, it is difficult to add even minimal allergy training to an overfull curriculum. We believe that the GMC should support allergy training and insist on its inclusion in the curriculum.

If GPs were upskilled in allergy, several million patients could be cared for in primary care

Creating more allergy consultants is the key to delivering allergy training to all medical students and will naturally lead to GPs having a better understanding of allergy. It is essential if 10 million patients are to be cared for exclusively in primary care and another five million are transferred back to primary care from specialists once a diagnosis and management plan is in place (as proposed in *The Nature and Extent of Allergy in the UK*, evidence in DH review of allergy services, 2006¹⁸).

We recognise the pressures GPs face and are suggesting small changes in learning. Improved awareness of allergy and a small increment in GP's allergy knowledge would be transformative.

The lack of consultant allergists directly impacts the amount of allergy training on offer to medical students

Key Recommendation

Increase the number of allergy consultants to better educate our doctors of the future.

The missing workforce

Creating consultants in adult and paediatric allergy supports the wider NHS workforce in delivering better care and is the first step to developing an allergy service fit for the 21st century

What is missing in allergy is a sufficient specialist workforce. The advantage of a cadre of specialist allergists (in adult and paediatric allergy) is that they not only provide the expertise required to deliver specialist care, but also support other providers and primary care. GPs and other healthcare professionals learn from their interactions with specialist allergists and gain experience to enable them to recognise allergy and support ongoing care.

Specialist allergists can also provide the teaching and guidelines required to upskill other healthcare professionals.

Allergy services in the UK are not fit for the 21st century

Creating consultant posts in allergy supports the wider NHS workforce

Healthcare professionals across the NHS learn from interaction with their specialist colleagues

This upskilling of the wider NHS workforce, including practice nurses and health visitors will be of immense value in the provision of equitable care.

Example - The impact of drug allergy

Due to the lack of allergists, most patients with drug allergy are not diagnosed, putting them at risk of re-exposure or resulting in the use of costly alternatives (general anaesthetic/hospital admission instead of a simple local anaesthetic). Nine out of 10 patients labelled as penicillin allergic are not allergic, but this results in use of expensive alternative antibiotics which can have side effects leading to additional illness and prolonged hospital stays, adding cost to the NHS⁴¹. However accurate diagnosis for those who are allergic is vital for safe care.

Other patients are sent to allergy services without the appropriate drug allergy expertise, creating risk if diagnosis is inaccurate. Drug allergy is complex and specialist and investigation requires considerable expertise and may in itself carry risk^{15,37}. Training should be delivered in specialist comprehensive drug allergy services with a high volume of drug allergy patients and expertise in the major categories of drug allergy.

Too often patients have to be sent to a service without the required drug allergy expertise.

A lack of appropriate drug allergy referral can lead to a delay in urgent surgery.

Increased prevalence

Drug allergy has increased in prevalence and is a major part of specialist allergy practice. It is a complex allergy around which knowledge is expanding and the shared experience of experts in centres with high throughput is essential. The most common causes are antibiotics, pain killers (from opiates such as morphine to anti-inflammatory drugs e.g. ibuprofen and paracetamol) and drugs given during general anaesthesia. The increase is probably because of the increased use of medicines. For example, antibiotics are given routinely in surgery and patients with recurrent severe infections e.g. chest infections are on intravenous antibiotics at home. But more recently new drug allergies are emerging, eg to the new biologicals, cancer drugs and most recently covid vaccines.

Poor access to specialist care

Drug allergy can be difficult to diagnose and requires expertise, developed from extensive experience. This is a specialist area in allergy. Erroneous diagnosis or a failure to accurately record and access an allergy investigation, may lead to re-exposure, with the risk of a severe reaction. Penicillins are the commonest cause of drug-induced death in hospital, as a result of catastrophic anaphylaxis.

Cost to patients

A patient who had anaphylaxis during general anaesthesia may wait many months or years to get an allergy referral and then may be referred to a service without appropriate competencies. If an anaesthetic is required in the meantime e.g. for emergency surgery, there is risk of inducing life-threatening anaphylaxis if the culprit drug is re-administered. As a consequence, some patients are waiting for urgent cancer or other surgery, as their operation was abandoned because of a severe anaphylactic reaction before the surgery could be done.

The risks around the lack of a drug allergy diagnosis applies to all types of drug allergy including pain killers, ranging from NSAIDs to morphine, local and general anaesthetics, antibiotics, and radio-contrast media used in specialist X-rays and scans.

While allergy to insulin is rare, it is inevitably very serious for people with diabetes. In this case, access to a specialist allergist is vital in order to identify a safe alternative.

Cost to the NHS related to misdiagnosis of a drug allergy

10% of the population is labelled as having a penicillin allergy (~5.7 million), but only 10% of this group is actually allergic (570,000).

This means that nine out of 10 of these people are avoiding penicillin and they are doing so needlessly. As a result more costly alternative antibiotics are prescribed. This, in turn, can lead to additional infection, for example *C. difficile* or other antibiotic resistant infections, and resultant prolonged hospital stays.⁴¹ The BSACI are now leading a 'penicillin de-labelling' project.

NAP6, a national audit of anaphylaxis related to anaesthesia by the Royal College of Anaesthetists, showed that allergy investigation of this life-threatening problem was inadequate. Adherence to the national allergy guidelines was poor (in 83%), and the audit confirmed deficiencies in service availability, capacity and reporting. Only 10% of assessments were considered 'good'⁴². This may be related to services where allergy is a sub-specialty, or services without sufficient volume or expertise in this area, having to take on these patients.

In patients with anaphylaxis during an anaesthetic, allergy investigation was poor in 41% - suggesting a lack of allergy services with the right expertise

Nine out of 10 patients labelled as allergic to penicillin are not allergic

Immunotherapy

The provision of immunotherapy in the UK, the only disease modifying treatment in allergy, falls far below the poorest countries in the EU.

International best practice for immunotherapy treatment for allergic rhinitis: patients fulfilling criteria in Europe or US are 200 times more likely to receive immunotherapy than UK patients

Immunotherapy (desensitisation) is a unique treatment for allergic disease. Unlike the use of standard symptom relieving medicines, immunotherapy is the only disease modifying treatment to down regulate or 'switch off' an allergy. The clinical benefits, with reduction of symptoms and medication use, persist after the treatment period. Immunotherapy is available to treat several allergies including those caused by grass and tree pollens and insect sting venom from bees and wasps. Immunotherapy for food allergy is also becoming available.

Traditionally, immunotherapy is administered as a course of subcutaneous injections (SCIT). More recently, immunotherapy can be administered by mouth, either as daily sublingual tablets or drops (sublingual immunotherapy or SLIT). The benefit of SLIT is that patients receive treatment at home after taking the first dose under medical supervision, thus many fewer hospital visits, with a reduced risk of a serious systemic adverse reaction compared to subcutaneous immunotherapy (SCIT). Bizarrely though, commissioning arrangements often fail and funding is not available to the many patients distant from a specialist centre.

Immunotherapy is offered to patients with severe rhinitis not controlled by optimal medical therapy or for anaphylaxis due to bee or wasp stings. Despite the advantages of immunotherapy as a treatment option for allergic disease, it is estimated that only about 4,000 patients in the UK are currently being treated, a fraction of those who should be able to access this therapy. Licensed SCIT and SLIT products have been shown to be effective in clinical trials for seasonal and perennial allergic rhinitis and are part of routine allergy practice worldwide.⁴³ The lack of allergists means that the criteria (ie barriers) to access these treatments for hay fever are very high and patients suffer, are unable to work or go out of doors.

NICE guidance recommends Pharmedgen venom immunotherapy as an option for the treatment of bee or wasp venom allergy if it is severe or if there are other risk factors (this product has been replaced by Alutard SQ venom). Venom anaphylaxis is severe and occasionally fatal. It is estimated that about 1% of the adult population are at risk of anaphylaxis after a bee or wasp sting.¹⁸ Taking a conservative estimate, that 20% of 1% of adults were eligible for venom immunotherapy, this equates to 9,500 adults.

However, despite the NICE guidance published in 2012 there is only an estimated 700 patients across the UK undergoing this immunotherapy treatment, 7 in every 100 of those eligible. This

very small number of people receiving immunotherapy in the UK compared with immunotherapy treatment in European countries and in the United States puts the paucity of allergy services in the UK in sharp focus, highlighting the lack of awareness of this life-saving treatment in primary care and of specialist allergy services.

There is a large discrepancy between the use of immunotherapy across Europe compared with the UK. A recent study from Germany found that 7% of the adult population with allergic rhinitis was treated with immunotherapy. Based on the knowledge of prevalence and the number with severe and poorly controlled disease in the UK, an estimated 0.03% of eligible adults with rhinitis receive immunotherapy^{24,44}. This is in stark contrast to the figure for Germany. A national audit shows that there is likely a large 'Unmet Need' for allergen immunotherapy treatment of children with severe allergic rhinitis, whose lives are affected significantly by the condition.⁴⁵ Only 323 children had been treated across centres in England over 10 years. Extrapolating to data in adults, a crude estimate would be that only 1% of eligible children are receiving immunotherapy. As the disease is not as severe in children as adults, a more cautious estimate would be that only 10-20% of eligible children are being treated. Thus 8 in 10 children with severe disease are denied this therapy. Immunotherapy is the only treatment that improves the long-term natural history of allergic rhinitis, with reduction in symptoms and medication use. Moreover, SIT has other beneficial effects, reducing the progression of rhinitis to asthma and the development of new inhalant sensitization.

**Only 7 in
100 eligible
patients receive
immunotherapy
for venom
anaphylaxis**

Looking to the future

Little progress has been made in the provision of immunotherapy since the Royal College of Physicians and subsequent reports^{1,3,5}.

Research has progressed and in the future new possibilities will open for treating a wider range of patient groups with immunotherapy. Recent advances have shown that house dust mite SLIT is effective for rhinitis and can prevent exacerbations of allergic asthma in adults and a new product, Acarizax is licensed in UK^{46,47}. There are other examples. SLIT offers effective treatment with few hospital visits, yet the lack of a co-ordinated national commissioning system for immunotherapy across England is failing patients.

UK studies have also shown promising early results in treating peanut allergy in children, with 85-91% success¹¹. This treatment is already being used with 95% success as an unlicensed medicine in the UK. A phase 3 trial of another peanut immunotherapy product, Palforzia, in the US was successful and a product licence has been granted⁴⁸. As many as one in 70 children have peanut allergy⁴⁹ and immunotherapy offers lifechanging benefit allowing them to live without the constant fear of a serious allergic reaction.

Key Recommendation

Improve access to immunotherapy for patients who would benefit.

Sensible commissioning arrangements so that patients who live far from the specialist centre can be offered SLIT.

Commissioning

Commissioners are often not aware of the allergy needs of their population nor that allergy is a full speciality. There should be clear referral pathways to both adult and paediatric specialist allergy care.

Many CCGs are now looking at population-based healthcare, dividing their GP networks into areas covering populations of between 30-50,000, a number which is considered to allow better coordination of care. It is important that they are fully aware of the increasing numbers of both children and adults living with allergic disease and ensure that they are commissioning appropriate services throughout the patient journey having identified specialist and local services, so that appropriate referral can be made.

A survey of commissioners conducted by NASG in 2004 showed that few specifically commissioned allergy and that some wrongly assumed allergy would be dealt with by other specialities. It seems likely that not all commissioners are aware that allergy is a full speciality; nor that one in three of their population have an allergy-related disease. Recent work by Allergy UK with CCGs over appropriate prescribing of infant formulae for infants with cow's milk allergy, revealed that CCGs had little understanding of cow's milk allergy, how it differed from lactose intolerance and how some infants were wholly reliant on specialist hypoallergenic formula. Such poor understanding can also easily lead to inappropriate, costly overuse of specialist formula where it is not necessary. This Allergy UK/BSACI project led to considerable cost savings, which could be replicated around the country.

The unmet need of people living with allergy may become obvious through long waiting times, even worse post-COVID, reflecting lack of services. Commissioners should ensure there is an age specific specialist allergy service to which those with suspected anaphylaxis or drug allergy or in need of immunotherapy can be referred, as recommended by NICE ^{22,41}.

Commissioners are often not aware of the allergy needs of their population

Commissioners do not always recognise allergy as a full speciality

Sustainability and Transformation Plans and the Integrated Care Systems should ensure patients in their locality are getting quality care which is in line with guidance, for example that produced by NICE. Specifically this could include auditing to gauge if quality standards for food allergy and anaphylaxis are being met, or even if the services are available to allow them to be fulfilled. However, in many areas appropriate allergy services with the right skills are inadequate. As outlined above, the solution to improving allergy care is in the development of better services in teaching hospitals and management in primary

care, so they can work together as part of a joined up system. An integrated care model should be developed to allow more cases to be managed in primary care. Critically this would require healthcare professionals in primary care to be up-skilled in allergy but specialists are also essential to underpin integrated care⁵⁰. They provide advice and guidance to GPs, reducing referrals, providing education and support for primary and secondary care and developing guidelines and local pathways. So the creation and development of more specialist allergy centres is fundamental to the improvement of allergy knowledge and understanding in primary care.

Up-skilling in primary care should lead to improved quality in care for patients with mild to moderate allergic disease, with management in the community where appropriate, and referral to secondary or tertiary care for those with severe or multi-system disease and specialist problems, such as drug allergy or complex food allergy. Improved knowledge results in cost savings for example more appropriate prescribing of infant formulas for milk allergy (where expensive amino acid formulas have been prescribed when continued breast feeding or cheaper formulas were appropriate); specific IgE blood tests being appropriately requested; referrals only when indicated by NICE guidance; and management of more patients in the community reducing referrals). Better allergy care also leads to reduced A&E attendances. The new capitated base care funding encourages the management and prevention of allergy related problems before referral, rather than funding repeat outpatient attendances. The NHS long-term plan and Five Year Forward View with integrated care supports the development of primary care services and allergy is a prime candidate within this development strategy.

The lack of specialist allergy services creates long waiting times and prolonged morbidity

Key Recommendation

Commissioners to be aware of the allergy needs of their population.

National and local commissioning plans for allergy to be in place.

Ensure clear referral pathways to both adult and paediatric allergy and support more allergy care to be delivered in a community setting.

The healthcare community

Some training in allergy for established GPs and allied healthcare professionals is not mandatory and their knowledge, for the most part, is poor or limited. Improved knowledge of allergy would mean more patients have their allergy recognised and the burden of disease reduced; and more patients could be treated nearer to home.

Community Health Care teams are crucial in the seamless management of those with allergic conditions, but they need to work with GPs who have some knowledge of allergy, with access to specialists for referral or advice. The unique potential for the management of allergy by allied healthcare professionals remains untapped and wider formal support in their roles would benefit patients.

One of the outcomes of the DH review of allergy services, 2006, was to set up the Skills for Health project in Allergy, defining competencies in allergy for allied health professionals^{4,51}.

Health Visitors and Midwives

Health visitors and midwives should be aware of, and be able to recognise and advise, on the presenting symptoms of food allergy in infants, given the data on failure to recognise this with unacceptably long delays to diagnosis.

Pharmacists are essential for advice on self-management and could play a role in adrenaline autoinjector training

Pharmacists

Pharmacists are often the first healthcare professionals consulted for health advice, and in line with current strategies this group can play an important role in advising appropriately on the self-management of allergic conditions such as hay fever and guiding those who may have a diagnosis but would benefit from more help and advice for example, training/checking on how to administer adrenaline devices. They can also 'signpost' to patient organisations who support those living with allergic disease.

Nurses

The role of asthma nurses could extend, with training, to become asthma and allergy nurses. Practice nurses, carrying out routine asthma checks should be asking about allergies and assessing for triggers in those for whom allergy may be exacerbating symptoms. Poorly controlled asthma is a risk factor for fatal food induced anaphylaxis,

so nurses have a unique opportunity to explore asthma triggers and advise on good control. There also needs to be awareness of associated and multi-system features of allergic disease e.g. eczema and rhinitis which commonly go unrecognised as part of the allergic picture. At first prescription and ideally re-prescription of an adrenaline auto-injector patients should receive practical training by the nurse using a 'practice pen'. This could be a role for the asthma/allergy nurse.

Dietitians

Dietitians have an important role in food allergy in children and adults. Most community dietitians are expert dietitians but have not been trained in allergy. Increasing the number of dietitians with some allergy training is much needed, particularly in the community. BSACI have a specialist dietetic group, bringing specialist allergy dietitians together and working with the British Dietetic Association (BDA).

Back to training

Training in allergy needs to become part of the core training of each group of healthcare professionals. As undergraduate medical schools are moving to a generic final medical examination, we need to ensure that allergy becomes examined within this and is therefore part of the curriculum and taught at undergraduate level. A cadre of consultant allergists could fill this role.

Revalidation and personal development are important in the careers of all healthcare professionals, but what they choose to learn is often guided by what they feel they need to know. Unfortunately, in the current climate of low awareness and understanding, one of the most challenging issues is creating an environment in which allergy learning is perceived as a priority education asset. In this respect, education around allergy should play a part of mandatory learning, for example, completing an on-line module/attending a training meeting. There are already many on-line modules and other face to face training opportunities in allergy.

Additionally, there needs to be a drive to improve awareness of the current Guidelines on allergic disease. They are not implemented, or even known, by many healthcare professionals and this should be addressed as a priority.

Mind the gap – the need for a National Allergy Strategy

It is surprising that, given the scale of allergic disease, the modern NHS lacks a national policy to drive allergy services. This has left a gap in which anyone can set up an allergy clinic (usually in relation to their own speciality) without appropriate training. The combination of the lack of specialists and the general lack of understanding of allergy in the NHS, means that patients are referred inappropriately and see a series of specialists whereas a single allergy consultation would be more effective.

Extending the role of the asthma nurse to cover allergy would help with long term management and could lessen the risk of severe reactions



Improved knowledge in primary care would mean more patients would have their allergy recognised and allow them to manage the condition themselves

As an example of this is the ENT surgeon, expert in his own field, who set up an allergy clinic to deal with rhinitis only to receive a referral of a child with peanut allergy. He confirmed this by a blood test and replied to the GP 'I can confirm this child has peanut allergy' but provided no guidance on treatment or management. The family assumed they had received good treatment. As a comparison, there is no way that any doctor could set up a cardiology clinic without training in cardiology.

Previous reports have highlighted the need for an overarching plan for allergy services that draws on the already strong collaborations between key stakeholders such as the BSACI, Allergy UK and the Anaphylaxis Campaign. There is excellent precedent for this approach in other developed countries suffering high prevalence of allergic disease. In Australia, the Australian Society of Clinical Immunology & Allergy (ASCI) together with Allergy & Anaphylaxis Australia worked in collaboration with other stakeholders to develop the first National Allergy Strategy in 2015. This document was developed to improve the health and quality of life of Australians with allergic diseases and minimise the burden of

allergic diseases on individuals, their carers, healthcare services and the community. It focussed on defining measurable, achievable and realistic targeted goals in the key areas of Standards of Care, Access to Care, Information, Education and Training, Research and Prioritised Chronic Disease. Development of such a plan for the UK would not be expensive, as the stakeholders are already fully engaged and would just need the project management support and engagement of government agencies to achieve something similar. Fundamental to this is to establish a core of specialist allergists and specialist services. This would provide the detailed road map required for the implementation of a more effective long term allergy strategy.

Key Recommendation

Improve allergy knowledge for community healthcare professionals.

Living with allergy

Prescription charges

NHSE Guidance on the conditions for which over the counter items should not be routinely prescribed in primary care has a potential impact on people living with allergic disease. Allergy UK, together with the then president of BSACI, wrote to over 200 CCGs throughout England in August 2018 expressing their collective concerns about the implementation of these Guidelines. These concerns focused, in particular, on the terms 'self-limiting', 'minor illness' and 'mild to moderate' in the context of long term allergic conditions, specifically atopic dermatitis, seasonal and perennial allergic rhinitis and allergic eye conditions. The definition of these terms was unclear and liable to misunderstanding and misinterpretation and the letter outlined how these guidelines could be clarified so that those living with chronic allergic disease continue to receive the most appropriate treatment for their symptoms on prescription.

While the direct response from CCGs was low (less than 5%) the general consensus was that patient communication (both through literature and face to face with their GP) was crucial in clarifying the guidance and avoiding inequitable treatment of those with allergic disease through the removal from prescription of otc medication that effectively treated their long term condition.

How allergy impacts on everyday life

Allergy is a complex condition and whilst some allergic disorders such as hay fever can mostly be managed by the individual, a proportion of these cases are severe and poorly controlled with a major impact on the patient's life. Some adults are unable to work, in others vision is affected or they cannot go outdoors. The performance of school children with hay fever is consistently lower on days with high pollen counts, often leading to a drop in grades from the mock exams taken early in the year to the exams sat in the summertime.⁵² Poorly managed rhinitis affects concentration and ability to work at school. Eczema and asthma can cause major disruption to daily life with an individual having to be aware of many environmental factors to manage their condition. There is constant misery from itching, wheezing, coughing or itchy sore eyes. At the extreme end of the allergic spectrum is anaphylaxis, a severe and potentially life threatening reaction. For people at risk of anaphylaxis or who care for a severely allergic child the constant fear of an allergic reaction can make living a normal life very difficult. Every time a child eats creates anxiety with an enormous impact on the whole family.

Allergy UK's Living in Fear Report states that 44% of allergy sufferers are living in fear of a potentially fatal reaction, leading to anxiety over the most basic everyday activities such as eating or even leaving the house.⁵³

Penny Watson, 22, has a severe peanut and nut allergy. She tries to lead a normal life like any other young person but the fear of having a reaction can sometimes take over.

"I go out clubbing on weekends and eat in restaurants but I have to be so careful. When you have to watch everything you eat, watch what other people are eating near you and revolve your lifestyle around your allergy to stay alive, it is a very scary pressure to live with.

"I am very anxious about my allergy, I have to be, so you're always living in fear. You start thinking you are allergic to everything as everything you put in your mouth becomes a threat.

"It controls my life and as long as I have control it is fine. It is when you lose control that's when your allergy becomes scary. That's when anxiety and fear come in. You no longer have control of your life – it's not just a reaction, it's your life."⁵³

For those living with a drug allergy, receiving medical treatment can be very risky. It is estimated there are 10 deaths per year in the United Kingdom caused by drug anaphylaxis during anesthesia alone.⁴² Much larger numbers have severe reactions to a range of drugs but particularly antibiotics and pain killers, placing them at risk and restricting treatment options. Alternative medication is required which may be less effective, more expensive or in some cases not as safe. Surgery is also a risk which adds to the impact on a patient's life.

62% of allergy sufferers said their allergy "significantly affected all aspects of their lives"

For people living with food allergy there are many risk factors including ensuring those around you are aware of the potential risks. In peanut allergy, mistaken exposure, with a further allergic reaction, occurs in between 14% and 50% of patients each year. The Food Standards Agency reports that shopping can take on average 39% longer and cost 11% more for peanut allergic consumers⁵⁴ and despite changes in the law which now require all food outlets to list allergens contained within the food they serve, eating out can still increase anxiety and make socializing difficult. This is particularly true for teenagers and young adults who may not want to draw attention to their condition and, as a result, take dangerous risks. Coroners' cases of food allergy deaths reveal the failure of food outlets to correctly identify allergens in the food being served; and the tragic death of

Natasha Ednan-Laperouse following a reaction to sesame in a baguette from Pret a Manger, highlighted the difficulties faced by patients with food allergy in choosing their food safely. This has prompted swift action by DEFRA to find ways to improve the information provided on food packed on a food outlets' premises and led to legislation that requires all food businesses to include full ingredients labelling on pre-packaged food.

Allergy doesn't just pose a risk to health, it also makes it difficult to live a normal life. For children in particular, this impacts on all aspects of their lives, such as playing outside and attending parties. One study shows that children with peanut allergy had higher anxiety levels and had their quality of life impaired to a greater extent than children suffering from insulin-dependent diabetes.⁵⁵

It is also being increasingly recognized that an episode of anaphylaxis could be considered a traumatic event that may lead to Post Traumatic Stress Disorder (PTSD) and has been shown to do so in over 40% of adults who suffered an anaphylaxis.⁵⁶

The patient charity Allergy UK surveyed 6,000 allergy sufferers and found that over 62% felt their allergy "significantly affected all aspects of their lives".

The essential role of patient organisations

Patient charities Allergy UK and The Anaphylaxis Campaign are essential in helping people gain information which enables them to manage their condition and reduce their anxiety. Between them they have over 75,000 supporters with many more accessing their numerous services. Their campaigns range from schools, and food service education to ensuring specialist infant formula remains available by prescription.

Both organisations run a Helpline providing support and information to people living with allergy, with many callers reporting that these Helplines' have provided information they had not been able to access from the NHS.

Over half of the enquiries Anaphylaxis Campaign receive to their Helpline are from those with allergies themselves or parents and carers of children with allergies. Queries regarding allergies to food are much more common than queries relating to allergies to non-food allergens. The most common topics enquired about are:

- How to get referred to an allergy service
- Travelling with an allergy
- Adrenaline auto-injectors
- Allergen labelling on food products
- Psychological support

16% of the Helpline enquiries received by Anaphylaxis Campaign are from school headteachers and school nurses, particularly at the beginning of the school year, where they see queries triple for advice on how best to support pupils at school with severe allergies. These include questions on how to obtain a spare adrenaline auto-injector (AAI) device, training on use of an AAI, Making Schools Safer campaign resources, and their opinion on banning allergens at school.

Allergy UK's Helpline received an average of 192 calls, 62 emails and 183 Webchat exchanges across April 19 – October 19, also an average of 1281 visits to their website allergyuk.org during the same period.

Allergy is a complex condition that can impact on all aspects of life

The four key patient requirements

- Access to primary care
- Access to specialist allergy care
- Continuity of care
- Emergency care

This was set out in an NASG campaign. 'What patients want' in 2004 to the Chief Medical Officer and DH. However for many patients there has been little improvement and allergy care remains inadequate.

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