



The Patient Journey for Allergic Disease and a Model of Allergy Service within the NHS

A paper prepared by the British Society for Allergy and Clinical Immunology for the
Department of Health Review of Allergy Services

Contents

Executive Summary and Recommendations	Page 2
Overview	4
Section 1: The Patient Journey: Referral Pathways for Patients with Allergic Disease	8
Special considerations in relation to Paediatric Allergy	10
Referral Pathways for Specific Allergic Conditions in Adults	13
Referral Pathways for Specific Allergic Conditions in Paediatric Practice	21
Section 2: Model of Service	29
References	37
Appendix: Specifications of an Allergy Centre	38

April 2006

Executive Summary and Recommendations

1. There is far greater need for allergy services in the NHS than currently served.
2. The burden of allergic disease is extensive (BSACI paper 'Nature and Extent of Allergy' [1]).
 - a. It is estimated that more than 47 million presentations of illness where allergy needs to be considered, will occur in more than 25 million people.
 - b. There is considerable co-morbidity (different expressions of allergy in the same individual), complexity and increasing severity of allergy.
 - c. More than half of this burden could be managed in primary care, provided that appropriate competencies and infrastructure can be developed.
3. Few existing allergy services are comprehensive. Most are limited in throughput, scope and depth of expertise, producing highly fragmented, *ad hoc*, and geographically inequitable pathways of patient care.
4. There are few training posts in allergy. The existence of a Royal College recognised CCT in allergy offers a direct route for the development of expertise, experience and clinical governance. This opportunity has not been taken up by the Department of Health; there has been minimal provision for new training posts from the manpower services committee and little or no encouragement for PCT commissioning of specialist allergy services.
5. Until the current allergy review, little attention has been paid to the cost savings and improved patient care that would accrue if allergy were to be managed effectively within the NHS; millions of pounds are currently lost, and patients are asked to undertake unnecessarily tortuous clinical journeys, as a result of poor allergy management.
6. Primary Care should deal with i. disorders which can be treated symptomatically without an allergy diagnosis and ii. a proportion of conditions, particularly asthma and rhinitis, caused by inhaled allergens, where an allergy diagnosis is required. iii. in addition many patients, after diagnosis and establishment of a management regime in specialist centres, will have ongoing care from their GPs.
7. However, primary care does not currently have the expertise/skills to improve the local provision of allergy care. There are no GPwSIs or other formalised ways of increasing allergy knowledge amongst primary care doctors, and no generic infrastructure to support the development of these prerequisites for an appropriate standard of care. Approaches to address ways to increase GP knowledge are the subject of a separate paper and meeting (National Allergy Strategy Group and Royal College of General Practitioners) [2].

The right pathways

8. In this paper ideal (*not* current) care pathways are set out. Referral pathways in conditions when an allergy diagnosis needs to be considered have been developed.
 - a. Referral to a specialist with expertise in allergy is required for anaphylaxis and severe forms of drug, food, latex and venom allergy and immunotherapy and multi-system allergic disease.
 - b. other conditions may sometimes also require referral depending on the clinical problem e.g. rhinitis, urticaria, angioedema

- c. Care for asthma and eczema will be provided by respiratory medicine and dermatology without need for an allergy diagnosis. A substantial proportion of patients with asthma and eczema should have an allergy diagnosis, and these need to be referred on to an appropriate allergy expert to supplement on going management.

Primary conditions for change - centres

9. To develop an appropriate model of care requires the establishment of geographically widespread allergy specialist centres, embracing and supporting existing secondary care stakeholders. This obvious and cost effective first step in the solution to the problem has been backed by the Royal College of Physicians [3].

10. The establishment of such centres would create the conditions for effective service integration – beginning to match capacity to need, de-fragmenting referral pathways, allowing training of junior doctors, GPs and allied health professionals, promoting clinical and basic research and encouraging the development of national guidelines and governance, and reducing overall healthcare costs. They provide efficient ways of treating large numbers of patients.

Primary conditions - training

11. The second key step is the development of a well-trained specialist allergy workforce. This requires the creation of more centrally funded adult and paediatric allergy training posts, as recommended by the Health Select Committee [4] and the Royal College of Physicians [3].

Overview

12. This paper follows two other submissions by the BSACI to the Department of Health Review of NHS allergy services. These submissions provided objective epidemiological evidence of the epidemic of socially disabling and potentially life-threatening allergic disease, evidence of the added value of organised specialist intervention and the incapacity of the existing NHS allergy services. The present paper sets out the BSACI plan for a model of the NHS allergy service, and describes optimal pathways of care within the proposed service. The essence of such an approach has already been endorsed by the Royal College of Physicians (see “Allergy: the Unmet Need” [3] and “Consultant Physicians Working with Patients” [5]).

13. The inadequacy of the NHS allergy service has arisen because, in contrast to other developed countries, allergy has only developed as a medical speciality in the UK in the last 3 decades, mainly with academic funding, and remains small. If the NHS is to “develop a service which offers high quality and personalised care to all its patients” (Department of Health, House of Commons Health Committee Report [4]) with respect to allergy, this situation must radically change. In the current health system it is difficult for small specialities to develop. The opportunity for change exists, provided by the recognition by the RCP/JCHMT/PMETB of allergy as a medical speciality with a structured training curriculum through which allergy specialists can now be trained. Unfortunately this opportunity has not yet been seized by the Department of Health; there is little encouragement for local PCT commissioning of services, and very little provision of new training posts from the DH Workforce Committees. Although there are only a relatively small number of centres where allergy trainees can receive training in the full spectrum of management of allergic disease, more training capacity exists. Allergy is a small component of the training curriculum of immunologists. The amount of allergy training undertaken by immunologists varies depending on their location, interests and career plans. Where allergy is intended to be a significant part of the consultant practice of any trainee we would suggest the need for a substantial increase in the amount of allergy training which could be achieved by an attachment to an allergy centre.

14. The lack of provision of a structured allergy service in the UK has had two major effects. First, medical undergraduates, non-specialist postgraduates and primary care physicians have very limited knowledge of allergic diseases. The BSACI has provided tangible evidence, accepted by all stakeholders, that there is limited understanding of allergic disease in primary care. This means that allergic diseases, many of which should appropriately be managed in primary care, are managed inefficiently. Many practitioners lack the confidence and the infrastructure to know when and how to manage these diseases themselves and when it is appropriate to refer. Secondly facilities for referral for a specialist allergy opinion have arisen in the UK on an *ad hoc* basis. There is at present only a small number of hospitals in England (but none in Wales, Scotland or Northern Ireland) which could currently be classified as having a fully resourced service (Allergy “Centres” as defined in part 2 of this document) equipped to deal with the full spectrum of allergic diseases seen in adults and children. Some of these centres do not receive dedicated NHS funding for clinical services and rely on academic funding. A proportion of allergy care is provided in a mix of organ based clinics and general allergy clinics which vary considerably in capacity and expertise resulting a fragmented and very variable level of service. While it goes without saying that the clinical care provided by these clinics is of value, they are often limited in terms of breadth of expertise, facilities for the performance of complex diagnostic procedures, capacity and funding. The inadequacies of existing allergy services to cope with the current allergy epidemic in an efficient and structured way are laid out later in this document, but we would strongly argue that this is any case self-evident.

15. Allergy in childhood deserves special consideration. It is in early life when allergy is at its most prevalent and complex and during this sensitive time of growth and development, children are particularly vulnerable. As with adults, there is great lack, and geographical inequality of provision of allergy services for children, resulting in fragmentation of referral pathways, and limited ability to diagnose and manage paediatric allergic disease in primary care. In fact, the current standard of the NHS allergy service for children fails against virtually every care standard set down by the National Service Framework for children, young children and maternity services. It is the nature of atopic disease in children to evolve and progress: the so-called “atopic march”. Piecemeal management of the elements of this march (eczema, food allergy, rhinitis and asthma), while feasible (and sometimes additionally necessary) by isolated, suitably trained paediatricians or other specialists, detracts from consideration of common allergic precipitants and strategies for early intervention, as well as the accrual of knowledge that might be used to direct helpful therapy, inform prognosis and reduce long term health care costs. Finally, it is clear that many children with allergic disease in the UK are being seen by clinicians who do not have adequate training, either in allergy or sometimes in the welfare of children. It is clearly imperative that a child with an allergic problem is seen by clinical services that have training both in allergy and in child health. The same is true of allied professional services such as dieticians or allergy nurse specialists. Provision of global care within, or under the umbrella of an allergy specialist centre will provide accurate initial diagnosis based on appropriate allergy testing with fully trained staff interpreting the data, coordinated management by physicians, community health care professionals and dieticians, and unique opportunities for research.

16. This paper, therefore, lays out the ideal (*not* the current) pathways of care of patients with allergic disease (section 1) and then provides data from the BSACI ongoing national survey of existing allergy services underlining the (grossly inadequate) current provision of service, followed by a description of the proposed increased infrastructure necessary to establish adequate referral pathways and patient capacity (section 2). The key feature proposed is the establishment of geographically strategically placed allergy specialist centres, which would liaise with and support existing allergy clinics and primary care. This is seen by the BSACI and the Royal College of Physicians and other stakeholders such as patient representative groups, as an obvious and effective solution to the problem of allergy care. The establishment of such centres would begin to match capacity to need, de-fragment referral pathways, allow training of junior doctors, GPs and allied health professionals, promote clinical and basic research, encourage the development of national guidelines and governance and reduce overall healthcare costs. These large allergy centres are the most efficient way of improving care at all levels.

17. Care pathways/ referral pathways in conditions when an allergy diagnosis needs to be considered have been developed, and can be summarised as follows:

- a. Referral to a specialist with expertise in the management of allergic disease is required for anaphylaxis and severe forms of drug, food, latex and venom allergy and immunotherapy and multi-system allergic disease.
- b. other conditions may sometimes require referral depending on the clinical problem e.g. rhinitis, urticaria, angioedema
- c. although the principal care for asthma and eczema will be provided by dermatology and respiratory medicine without need for an allergy diagnosis, a substantial proportion of patients with asthma and eczema should have an allergy diagnosis, and need to be referred to someone with appropriate allergy expertise.

18. Primary Care would deal with

- i. disorders which can be treated symptomatically without an allergy diagnosis and

- ii. a proportion of conditions, particularly asthma and rhinitis caused by inhaled allergens, where an allergy diagnosis is required.
- iii. in addition many patients, after diagnosis and management in specialist centres, will have ongoing care from their GP.

The burden of allergy: numbers and service implications

19. Estimates of the numbers of people with allergic disease, as well as the complexity and severity is made in the BSACI paper 'Nature and Extent of Allergy in the UK' [1]. Very large numbers of people with allergy, and indeed most people with severe allergy, suffer multiple disorders. However there are some limitations to the available data which only allow one to count individual *presentations of disease* (referred to in the paper as *disease episodes*), but only rarely allow counting of the numbers of multiply ill *people*, specifying the range of their disorders.

Recognising this and other problems, and interpreting available sources conservatively, BSACI's advice to the DH enquiry team is that the NHS in the UK should expect to be faced with allergy need as follows. Appropriate service planning needs to take account of these estimates and will have to schedule a response to the need through time.

SUMMARY from 'Nature and Extent of Allergy':

1. An estimated more than 47 million allergy disease episodes, translating to an estimated 20 million people with illness, requires allergy to be considered in diagnosis and disease management.
2. More than 21 million of these disease episodes, plus an unknown number of food allergy episodes, (translating to an estimated 10 million plus people) can be expected to self manage their allergy or be treated symptomatically within primary care without an allergy diagnosis.
3. An estimated 10 million people require an allergy diagnosis for effective care to be provided. This translates to some 20 million-disease episodes, many of which will be managed currently in the health service in isolation from each other as only minimal capacity exists to meet the allergic needs of the whole person.
4. Several million (we can be no more precise) of those who receive a diagnosis will be found not to have allergy. Many of these people, and their doctors, will be acting in the belief that they do have allergy – and will be restricting diet unnecessarily or taking expensive medication, or unnecessarily avoiding common drugs, in the false belief that these cause allergic reactions.
5. Well developed primary care can manage all those who need only symptomatic treatment. But with greater allergy expertise in primary care fewer symptomatic treatments would be “stepped up” without firstly considering allergy, and trigger avoidance, as a prior step. In addition, primary care might diagnose and manage up to 25% of those who need diagnosis and allergy management – primarily those who have a specific allergy caused by aeroallergens, without other complications. On this basis, primary care might be expected to become accountable for up to 12.5 million people, depending on the investment thought appropriate in developing diagnostic capacity in primary care. This translates to more than 25 million disease episodes. But, if managed efficiently and if the whole person is considered, the numbers of disease episodes would reduce down towards the

equivalent numbers of people with allergy.

6. Several counts might be made of the numbers requiring specialist allergy care. A conventional approach might be taken, and the residual number which cannot be coped with in primary care used. On this count, an estimated 7.5 million people (15 million disease episodes) need specialist help. Alternatively, using a more direct approach, based on the available evidence on prevalence and severity, we advise that a minimum of 7 million disease episodes, or more than 3.5 million people plus need specialist care – without including the need arising from drug allergy, angioedema and urticaria, where we do not have numbers. This gives a range of between 3.5 and 7.5 million people whose allergy needs require specialist help.
7. Because of the complex and pervasive co morbidity of allergic disorders, allergy centres capable of providing for a full range of possibilities – of sufficient size and with comprehensive expertise - are likely to be both more efficient and more clinically effective.

Section 1: The Patient Journey: Referral Pathways for Patients with Allergic Disease

1.0 Introduction

The current patient journey for someone with allergic disease is presently directed by the nature of the local service available rather than an optimal care pathway. As noted below patient and GP current referral choice is significantly constrained by the variability in provision in terms of both capacity and expertise. *It is important to keep in mind when reading this section that the referral pathways described below are not necessarily what currently happens, which in many cases is unsatisfactory, but is an optimal pathway that we would recommend in the context of an allergy service that, looking to the future, has been developed according to the model described in section 2 below.* Agreed local referral pathways based on national guidance will enable the development of local guidelines to optimize the patient journey towards the type of service that would be equipped to deal most effectively with their problem. In all cases an allergy centre would be best equipped to optimally diagnose and treat virtually any allergy related problem. In some cases either organ based services or general allergy services (that do not meet the specifications of an allergy centre) may be able to deal with the problem depending on local capacity and expertise. The allergy centres, as well as providing secondary care, act as a tertiary referral point, and interact with the local GPs to provide an educational and outreach platform (Figure 1).

There are several levels of care for people suffering from allergic disease. The direction of development for the NHS is towards increasing the choices for patients and the service capacity at all levels. Broadly we might distinguish between:

1.1 Self-Care:

Self care, informed by authoritative and widely available information and advice from primary care specialists and pharmacists offers great scope for patient empowerment in many areas including allergen avoidance, more efficient use of medicines and knowledge of what help is available from the NHS and charitable organisations, particularly Allergy UK and the Anaphylaxis Campaign. Self-care is feasible provided that the patient is equipped with an accurate diagnosis and has access to relevant information; including when it is appropriate re-explore specialist advice. The lack of good quality advice means that many patients turn to complementary approaches to diagnosis which have been demonstrated to be fallacious.

1.2 Primary Care:

Service provided by the general practitioner and clinic nurse in a primary care setting. This may operate at a variety of levels. Adding expertise into primary care, either through investing in training and/or by making specialist services directly available, while accountability remains with the primary care provider, enhances what can be done within these levels of care. The correct definition of primary care also includes self-referral to an acute emergency centre.

1.3 Emergency Care:

This refers to acute management of allergic disease presenting as an emergency either in the context of

emergency GP services or an A&E or medical admissions unit. Care provided by specialist nurses (NHS Direct), on call GPs, or emergency and general physicians. It is important that evidence based guidelines for management of such emergencies are widely disseminated and that patients receive appropriate specialist follow up.

1.4 Secondary Care:

Service provided by a consultant-led, multi-disciplinary team in a hospital setting. Within hospital care there is currently a wide range of level of service provided from those 'with an interest' through to consultants in allergy.

1.5 Tertiary Care:

This is defined as a service provided for patients with complex problems that require referral for specialist investigations or forms of management. Allergy centres offer this service and some general allergy clinics may offer aspects of this service for certain disorders. Comprehensive facilities for the management of both adults and children, as previously noted, are essential. A specialist centre is also a natural reservoir for highly specialised therapy such as drug desensitisation, and a natural focus for audit and innovative research.

Recommendations are made below for ways for incorporating and enhancing the currently available services into an effective network as well as promoting and enhancing the future training of a specialist cadre of Allergists to lead the service in the future.

1.6 Model of Care

In an optimal service self-caring patients should be those with mild intermittent symptoms where the diagnosis is clear (it is not always necessary to identify or confirm an allergic cause) and there is no risk of harm to their well being now or in the future. A typical example is mild seasonal allergic rhino-conjunctivitis, however, even with this scenario school and work performance can be compromised. With access to good information their symptoms can be managed adequately by OTC medication with advice from pharmacists. It is therefore important that information in the public domain is accurate, easily accessible and patient focussed. It is also important that community pharmacists are well trained in the management of allergic disease, aware of how to manage straightforward problems and when an assessment by a GP is required. This is clearly not being achieved currently. Patients often have to act virtually on their own without effective support from the NHS. One problem is the variable quality of advice available to the public, especially in the lay media, with over emphasis on alternative and complementary medical approaches to allergy diagnosis and care. An additional problem is the lack of formal training programmes for community based pharmacists in allergy.

When the condition becomes more troublesome patients will consult their GP who will make a diagnosis and instigate effective management, referring where necessary for more specialised diagnosis and help. This requires the following:

- Critically, a good basic understanding of allergic disease: This will be most effectively developed when allergic disease becomes a stronger aspect of training for work in primary care; and when allergy becomes a strong specialty in secondary and tertiary care to support ongoing development.

- The time to take a careful history and examine the patient.
- Access to investigations to determine if type 1 allergy may be involved, in particular by undertaking skin prick testing or specific IgE measurements. The former is not currently available in primary care and seems unlikely to become so except in a few practices with a specific interest because of the cost, lack of infrastructure/expertise to carry out tests and the lack of expertise in interpretation. Similarly, lack of expertise in interpretation limits the use of specific IgE testing. Without this access it is difficult, if not impossible, to make an accurate diagnosis of allergy in primary care. What is needed is not only access to tests but the ability to interpret the results. This type of service could be offered to primary care, for example through trained specialist allergy nurses working in primary care linked to a specialist allergy centre, which provides their training and CPD. It is clear at present that allergy tests in primary care (and in some secondary care services without appropriate expertise in interpretation) lead to confusion and misdiagnosis, because of inadequate knowledge of how to interpret them. The situation will probably become worse with the proliferation of near-patient point-of-care-testing screening devices.
- Expertise in management. This will vary depending on the condition. For example the evidence shows that the GP is likely to be confident in pharmacological treatment of asthma and atopic dermatitis (requiring no allergy related expertise) whereas expertise in drug allergy or food allergy in children will be more limited. Even with asthma and rhinitis GPs may be uncertain about the role of allergy and where measures such as allergen avoidance and immunotherapy fit in.

The point at which the GP considers it is appropriate to refer the patient on to a specialist will depend on a number of circumstances including:

- The expertise of the practice.
- The nature of the secondary and tertiary care service.
- The type of allergic condition involved.

Guidelines are required on when to refer; and GPs require access to appropriate secondary and tertiary care services.

The purpose of referral is to make an accurate diagnosis and advise, and where necessary direct, optimal disease management. For allergic disease this often only requires a single outpatient consultant visit. In many cases exclusion of allergy as a cause of the symptoms is as important as showing that allergy is involved. Identification of an offending allergen is a central part of any secondary and tertiary care service to provide a basis for allergen avoidance and immunotherapy. The increased complexity and multiple expressions of allergic disease in a single patient, means that management is more efficient in a specialist allergy centre with comprehensive expertise.

1.7 Special Considerations in Relation to Paediatric Allergy

Allergy in childhood deserves special consideration. It is in early life when allergy is at its most prevalent, severe and complex and during this sensitive time of growth and development children are particularly vulnerable. The largest allergy burden occurs in early life, with nearly half of all children reporting at least one current atopic symptom. The roots of adult allergic disease begin in infancy as

‘the allergic march’, with onset of eczema in infancy, followed by food allergy in toddlers, then asthma and rhinitis in school age children and finally adults. Allergies which appear to develop for the first time in adulthood e.g. allergic rhinitis usually occur on the background of multiple childhood allergic disease. This knowledge can be used to advantage and a detailed allergy assessment in at-risk infants can help to define the risk that allergic disease may strike later in life. For example, an infant with eczema who has evidence of persistent egg allergy is at increased risk of subsequent inhalant allergy and persistent wheeze (asthma) into adulthood. Similarly, detection of inhalant allergy in a wheezing infant indicates a high risk of persistent wheeze in later life. This knowledge may help to direct effective therapy, inform prognosis and reduce long term health care costs but is rarely acted upon at present.

The nature of the allergic march means that many allergic conditions commonly co-exist in a single child e.g. food allergy, asthma, eczema and rhinitis. Despite the complexity of multi-system disease, the underlying allergic cause of the different components can usually be diagnosed and managed by a suitably trained paediatrician. Often children are seen consecutively in several different clinics (e.g. general paediatrics, ENT, respiratory, dermatology) without ever considering the underlying condition in a global manner, increasing inefficient use of healthcare resources with a poor outcome for the patient. In cases of complex food allergy where identification of the allergen has not been attempted or achieved, infants diets may be inappropriately restricted (an apparently easy option), risking malnutrition, when also the offending allergen may still not have been identified.

A further difficulty is that the pattern and frequency of paediatric allergies have changed, with much more severe disease and greater co-morbidity. Peanut and nut allergy is the commonest cause of fatal and near-fatal food allergic reactions and is now commonplace amongst schoolchildren (1 in 70). New allergens are emerging such as kiwi fruit (having been identified rapidly by major allergy centres with large patient numbers), where a much higher proportion of reactions in children are life-threatening than those occurring in adults. Furthermore the burden of other common food allergies (egg and milk-where deaths have occurred in the UK) peaks in infancy. An allergy centre provides an essential service in this context; embracing diagnosis, provision of avoidance advice and management plans for accidental reactions which provide considerable reassurance and safety for families.

Older children suffer significant psychological stress because of their allergy. Those with severe food allergy have a more impaired quality of life than children with insulin dependent diabetes. Children with rhinitis and /or asthma have disturbed sleep, daytime lethargy and impaired cognition, with a demonstrable reduction in examination performance and therefore career attainment.

The national service framework for children, young people and maternity services has published national standards for child health and social care. The core standards required by the service are as follows:

- 1) Children, young people and their parents must have increased information, power and choice over the support and treatment they receive and they must be involved in the planning of their care and services.
- 2) A new child health promotion programme designed to promote health and well being of children pre-birth to adulthood is required.
- 3) Promotion of physical health, mental health and emotional well being by encouraging children and their families to develop healthy lifestyles is important.
- 4) There should be a focus on early intervention based on timely and comprehensive assessment of a child and their family’s needs.

- 5) There must be improved access to services for all children according to their needs particularly by co-locating services and developing managed local children's clinical networks for children who are ill or injured.
- 6) Health inequalities must be tackled to address the particular needs of communities and children and their families who are likely to achieve poor outcomes.
- 7) Promotion and safeguarding of the welfare of children ensuring that all staff dealing with them are suitably trained and aware of action to take if they have concerns about the child's welfare.
- 8) It is important to ensure that pregnant women receive high quality care throughout their pregnancy, have a normal childbirth wherever possible and are involved in decisions about what is best for them and have choices about how and where they give birth.

Reinterpreting these standards in relation to allergy indicates very clearly that the current state of the services in the UK fail on virtually every core standard. Presently children with allergy are seen by general paediatricians (where allergy is not a component of general or most subspecialty training) where no local allergy service exists or adult physicians with no training in the care of children. Thus there is grossly inadequate information available to families about allergic disease as they affect children and how such families might be empowered to handle the problem. There is precious little information made available on ways in which the impact of allergic disease might be reduced and this certainly has relevance to the promotion of healthy lifestyles as many strategies which have a general effect on health will equally impact on susceptibility to allergy. Early intervention is the essence of paediatric allergy practice but can only be effective if there is an accurate initial diagnosis based on appropriate allergy testing with fully trained staff interpreting the data obtained by investigation. There are clearly inequalities which are based on a postcode variability of availability of paediatric allergy services with very few comprehensive clinics available and at the moment only a few regions in the country having relevant networks. Finally, it is clear that many children with allergic disease in this country are being seen by clinicians who do not have adequate training either in allergy or sometimes in the welfare of children. It is clearly imperative that a child with an allergic problem is seen by clinical services that have training both in allergy and in child health. The same is true of the other personnel in the service. Thus dieticians must be trained in paediatric dietetics and have full insights into the implications of dietetics for allergy. Allergy nurse specialists must be both child health nursing trained and have additional training in allergy. No other pattern of care is now acceptable based on the outputs on the national service framework.

2.0 Referral Pathways for specific allergic conditions in adult practice

2.1. Allergy in asthma

2.1.1 Patient risk and stress:

Varies between patients from mild to seriously disruptive of quality of life; can be life threatening and it may vary over time for any one patient. It is important to identify or exclude allergy triggers in asthma - including aspirin-phenotype – and manage these appropriately.

2.1.2 Allergy Diagnosis:

Allergy diagnosis/phenotyping becomes particularly important under certain circumstances:-

- when asthma is part of multi-system disease, with e.g. rhinitis, eczema or food allergy,
- even if asthma presents as a single disorder, where an allergic trigger is suspected (such as food, drug or animal-induced asthma, seasonal, or thunderstorm asthma)
- with co existent food allergy or latex allergy which puts patients at high risk of severe reactions
- with nasal polyps
- where usual treatments are not effective (refractory asthma).
- Where patients wish to find out if a particular trigger (e.g. pets, occupation) is causing their asthma

2.1.3 Allergic Aspects of Management:

Potential allergens need to be identified by a careful history, and appropriate investigations including skin prick tests (SPT), specific IgE, and in some cases allergen challenge, detailed home peak flow readings and assessment of the home or work environment for potential triggers such as fungal allergens

2.1.4 Patient pathway:

- i. Most asthma is managed in primary care; some of these patients do not require an allergy diagnosis and others do (see 2.1.2). For reasons detailed elsewhere it is difficult to obtain a definitive assessment of allergy triggers in this setting. Approaches to enabling allergy assessment in primary care need to be developed.
- ii. In other patients where an allergy assessment was required, referral to an allergist or an allergy clinic with the appropriate expertise e.g. provided by a respiratory physician would be appropriate.
- iii. The many patients where allergy diagnosis is mandatory, with complex allergies or co-morbidities, would benefit from access to allergy expertise located in an allergy centre.
- iv some patients should be referred to a respiratory physician for ‘step up’ in pharmacological treatment. Poor control should trigger an allergy assessment (as outlined in ii. or iii. above)
- v. After an allergy diagnosis and management, patients should usually return to primary care or a respiratory physician, as appropriate, for long term care, unless there is a co-morbidity requiring management by an allergist.

The BSACI are committed to working with the British Thoracic Society to develop guidelines for the identification of such patients where specialist allergy advice will be most useful and will jointly develop referral pathways for such patients.

2.2 Rhinitis

2.2.1 Patient risk and stress

Varies from mild to severely disruptive of normal life. It is the commonest cause of time off work and school and inability to sleep. Symptoms may be confined to the nose and the eyes; but are commonly associated with asthma and eczema. May be associated with nasal polyps, which cause severe morbidity, and with NSAID /aspirin sensitivity. Triggers may be pollen, animals, dust mite occupational allergens. May be seasonal or perennial. Rhinitis co existing with asthma often goes unrecognized, even though concomitant treatment of rhinitis impacts on asthma management.

2.2.2 Diagnosis:

Mostly straightforward identification of triggers through case history and skin prick testing. Allergic cause of symptoms must be confirmed or ruled out. Occupational element may require specialist investigation.

2.2.3 Treatment: First line medication of isolated symptoms is often sufficient.

2.2.4 Patient pathway:

- i. many cases managed appropriately through self-medication or in primary care.
- ii. referral to an allergy service should be considered
 - where severe symptoms are not being controlled, needing systemic steroids, or
 - where there is multiple organ involvement (e.g. with asthma or eczema) or
 - where an allergic cause must be confirmed or refuted and this cannot be done in primary care.
- iii. Referral to ENT should be considered where surgery for polyps or secondary bacterial sinusitis is appropriate. Chronic nasal polyps should be dealt with by a comprehensive allergy service especially if associated with aspirin/NSAID sensitivity. This expertise would be found in an allergy centre or an organ-based allergy service with an ENT background.

2.3. Allergy in eczema

2.3.1 Patient risk and stress:

Atopic eczema whether mild or severe may occur as a single condition, or it may co exist with asthma, rhinitis, angioedema and/ or urticaria. Quality of life is impaired due to itch and loss of sleep as well as disfigurement by rash. It is often a severe debilitating and morale sapping disease leading to social isolation particularly in children. Secondary infection is common.

2.3.2 Diagnosis:

Contact dermatitis diagnosis is not addressed in this pathway: this is a role for dermatologists, who have expertise in this area and provide a patch test service (this is a delayed type allergic hypersensitivity disorder, not an IgE-mediated disorder). In practice many GPs are unsure as the diagnosis of a given skin complaint and may refer either to an allergist or dermatologist. The two disciplines need therefore to have a good working relationship to make a diagnosis and effect optimal management as efficiently as possible for a given patient.

Patients may benefit from an allergy diagnosis when they have eczema which is:-

- part of multi system disease;
- where an allergic cause is suspected;
- which does not respond to first line treatment and allergy is suspected
- when, as part of management, the cause (diagnosing or excluding allergy) needs to be investigated.

Allergy diagnosis in eczema is often complex. While skin prick tests and specific IgE may be helpful, they are confusing for the non-expert – more so in eczema than any other allergic disorder. However they often provide important clues and food allergy often plays a major role in disease exacerbations in infants and children which often goes unnoticed. Often carefully controlled trials of dietary exclusion and reintroduction are required which are poorly managed and non-standardised in many current services. Dietary assessment for nutritional adequacy is required if key foods have to be avoided long term.

2.3.3 Management:

Symptomatic treatment is first line; [self-] management based on trigger avoidance requires allergy-based diagnosis. Dietary assessment and support may be required.

2.3.4 Patient pathway:

- i. Most eczema is managed in primary care, where allergy diagnosis can add value.
- ii. At a secondary care level dermatologists and allergists should work closely together. For many cases of eczema the dermatologist is likely to be the first point of referral. The allergists particular role is identifying the role of allergy and this is most needed in patients where eczema co exists with asthma and / or rhinitis, and/or food allergy; or where a rigorous approach to allergen avoidance such as exclusion or elemental diets are being considered. Such a range of skills and resources is most likely to be present in an allergy centre.

2.4. Food allergy/ intolerance

2.4.1 Patient risk and stress:

Varies from mild to severe and life threatening; symptoms may be local (rash, tingling in the mouth) but more often multiple with asthma, angioedema, urticaria, vomiting. Triggers may vary; and include nuts, egg, milk, fish, fruit, seeds, wheat. New allergens are being identified in clinical practice. Interaction with asthma, anaphylaxis, angioedema, urticaria, and eczema. Individual patient risk may change over time. Some food allergies resolves in time, others persist, and new allergies develop.

2.4.2 Diagnosis:

Accurate diagnosis is essential. Incorrect diagnosis may protract patient exposure (with potential risk of severe reaction). It may lead to an unnecessarily restricted diet; Patients often decide their own course of action on this without clinical advice, or on the basis of poor advice. It may lead to psychological or nutritional problems. Accurate diagnosis requires extensive knowledge of food allergens - including valid allergen sources for testing, ability to perform and interpret skin tests or blood tests correctly and skills and facilities to perform safe food challenges.

2.4.3 Management:

Avoid the foods triggering the allergy; immaculate control of coexisting allergies especially asthma; provision of management plan with rescue medication. Avoidance e.g. of soy, or cow's milk protein or nuts is not straightforward for the patient or for parents of affected infants and children. Training and re-training is necessary on food allergen avoidance and self-management of anaphylaxis. Provision of advice on alternative foods. In children, training of school staff and assessment of diet for nutritional adequacy.

2.4.4 Patient pathway:

- i. appropriate to manage in primary care when:- cause can be isolated; avoidance is straightforward; the doctor is confident in management and the symptoms are local and mild with no issues of cross-reactivity posing other risks to patient.
- ii. referral to an allergy service is essential when there are several possible causes; when the cause(s) significantly affect dietary options or avoidance is complex/ not easy; when symptoms

are severe or potentially severe; and/or allergy known to carry risk of a severe or systemic reaction (including concomitant asthma). To be effective, an allergy service must have clinical competence in asthma, anaphylaxis, angioedema, urticaria and eczema management. Since the range of foods causing allergy is increasing, a sufficient volume of work needs to be undertaken to identify new presentations of the illness and to undertake research. Such a range of skills and resources is only likely to be present in an allergy centre. Competence is also required to advise on/supervise reintroduction for foods such as egg and milk where resolution is common, but far from universal, in children. Proper risk assessment, support and reassurance is best provided by an experienced allergy centre.

2.5. Anaphylaxis

2.5.1. Patient risk and stress:

Both high – death can be a consequence; sensation of impending doom common; often repeat A&E attendances; severe emotional instability, when diagnosis is left uncertain or no clear management strategy. Stress particularly high when a child is involved. Major impact on daily life, school, social life and work.

2.5.2 Diagnosis:

Complex; involves possible drug, food, latex, venom allergy and physical and idiopathic non-IgE mediated anaphylaxis; asthma often implicated. Crucial to identify cause. Investigation and tests therefore required across a wide range of allergy; challenge testing may be required.

2.5.3. Management:

Avoidance of triggers essential, and may be complex requiring a high level of expert input and support. Access to rescue therapy and/ or preventative medication necessary for all patients; prescription of medication without accurate identification of cause and, importantly, a full management package is not appropriate for such a severe and complex disease. Management package includes training in avoidance of the trigger, use of self-medication, written treatment plans and training of school staff and availability of extensive and patient-friendly information.

2.5.4. Patient pathway:

- i. referral from primary care for accurate diagnosis and management essential in **all cases**
- ii. to be effective an allergy service must have clinical competence in drug/ food / latex / venom / idiopathic, physical anaphylaxis and provide a safe environment for challenge testing, as well as competence in asthma diagnosis and treatment. It is essential to refer to a service providing for a comprehensive range of allergy which is able to specialise in anaphylaxis management. Allergy centres and some allergy clinics (for example, for some but not all causes) would have such expertise.

2.6 Latex allergy and other occupational allergies.

2.6.1 Patient risk and stress:

Variable severity but lack of understanding amongst hospital doctors exaggerates risk and create fear and anxiety. Most patients have mild to moderate allergy, which should be easily managed but commonly doctors induce inappropriate fear and unnecessary complexity in management. But for some patients there is high risk (anaphylaxis) especially during medical interventions. Experienced risk assessment should be provided by allergy centres.

2.6.2 Diagnosis:

Clinical skills and experience paramount

2.6.3 Treatment:

Avoidance of latex exposure is essential. In some patients this requires occupational avoidance measures in workplace; planned management during medical interventions; emergency treatment plans for inadvertent exposure; control of asthma, eczema and associated food allergies. Most of those occupationally affected are health care workers. With expert advice virtually all patients can continue in the health service, but a common outcome is poor advice in secondary care and loss of employment.

2.6.4 Patient pathway:

- i.* referral to an appropriate allergy service for all patients
- ii.* to be effective allergy service requires competence in latex and food allergy, asthma and eczema. Such competence is likely to be found in allergy centres and some allergy clinics. Some patients present to an occupational health service and are referred on to an allergy centre, often with the use of pre-arranged proformas.
- iii.* Dermatologists often have an important role in the provision of a service in the diagnosis and management of patients with latex allergy, which often co-exists with eczema. Dermatologists are specifically trained in contact dermatitis including the diagnosis and management of occupational dermatitis, but these are distinct from latex allergy. Rubber dermatitis, a contact dermatitis triggered by exposure to latex rubber, needs to be distinguished from latex allergy and is dealt with by dermatologists, and confirmed by patch testing.

2.7 Urticaria

2.7.1 Patient risk and stress:

Severity varies from mild to severe, with impaired quality of life due to intense itching, loss of sleep and disfigurement by rash. Impaired concentration and loss of time from work, social impairment with loss of morale and self-confidence. Suspicion of an allergic cause often leads to ad hoc and frequently inappropriate avoidance, often of foods, without diagnosis. Distress due to always searching for a cause. Little help is offered by the NHS at present, but if an allergic cause is identified or ruled out, this can be of enormous benefit. and rationalize risk assessment and management.

2.7.2 Diagnosis:

Requires experience and appropriate clinical skills. Interpretation of tests may be difficult. Role of an allergy service is to phenotype the disease; allergy is usually being ruled out, but this means the search for an allergic trigger and inappropriate avoidance can stop.

2.7.3 Treatment:

Drug treatment; avoidance when trigger confirmed. If food or drug allergy need to be considered, trials of dietary exclusion/ reintroduction and challenge testing may be required.

2.7.4 Patient pathway

- i.* simple acute urticaria dealt with in primary care
- ii.* referral to allergy service when:
 - allergic trigger (latex, food, venom, aeroallergen, drug) suspected,
 - in order to exclude or confirm allergy;
 - when there is co existing angioedema;
 - the disease is difficult to control with standard therapy.

The allergy service requires skills in food latex, venom and drug allergy. Allergy centres, the majority of allergy clinics and organ-based clinics with a dermatology background will have expertise in urticaria. However if food or drug challenge is needed, referral to a specialist allergy clinic with appropriate facilities is required.

iii referral to a dermatology service particularly for symptomatic 'step up' pharmacological treatment and when an allergy diagnosis does not need to be considered.

Allergists and dermatologists may both be involved in the management of patients with urticaria.

2.8 Angioedema

2.8.1 Patient risk and stress:

Swelling of the subcutaneous tissues may be an isolated reaction, or constantly recurring over a long time. It may also involve the mucous membranes e.g. of the airway causing severe breathing difficulty or of the gastro-intestinal tract causing abdominal pain and vomiting. Varied severity from mild to severe with impaired quality of life due to disfigurement by facial swelling, unpredictability of time of onset of next attack (including during the night causing asphyxia) and loss of time from work. When it occurs in the mouth, tongue, larynx or is systemic and widespread it can be life threatening. It may be part of a multi system reaction involving airways and anaphylaxis as well as the skin.

2.8.2 Diagnosis:

Requires predominantly clinical skills (variations in presentation often indicate the type or cause of angioedema) and particular expertise in interpreting allergy tests. If drug allergy is suspected, specialist investigation or a challenge test may be required.

2.8.3 Management:

Drug treatment; management plans for self-treatment of attacks; avoidance of triggers e.g. drug

2.8.4 Patient Pathway:

i. If mild and not involving the airway; and not persistent may be managed in primary care

ii. Referral to an appropriate allergy or immunology service is essential when: -

- suspected allergy needs to be confirmed or excluded (particularly if challenge or other confirmatory investigation is required);
- there is an hereditary component; (care may also provided by immunologists in services provided by Primary Immunodeficiency centres and some dermatologists with an interest);
- it is part of multi-system disease (particularly if there is tongue or other airways involvement).

Allergy centres and the majority of allergy clinics should have this expertise. Some patients will have to be referred to specialist allergy centres e.g. if drug investigation/challenge required

iii. Dermatologists often see patients with angioedema, which frequently co-exists with urticaria. This is appropriate if allergy does not need to be considered.

2.9. Drug allergy (general or local anaesthetic allergy; antibiotic allergy; aspirin/NSAID sensitivity; opioid intolerance; others).

2.9.1. Patient risk and stress:

Variable, as between patients, from mild to life threatening reactions. Where symptoms are mild (certain types of rash), and if therapeutic alternatives are available, appropriate simply to avoid prescribing the drug. (However, substantial NHS costs are involved when, for example, patients are labelled as allergic to penicillin, and prescribed alternative antibiotics without proper testing –). Need for accurate diagnosis increases with i. severity of reaction (e.g. rash and angioedema,

anaphylaxis, rash causing severe illness) and/or ii. when several drugs are implicated in causing a reaction (e.g. during anaesthesia. Complexity of the illness and the diagnosis is increased because of multiple drug reactions and cross-reaction between drugs.

2.9.2. Diagnosis:

When this is required, it can be complex. It cannot be done from a blood test alone. Accurate diagnosis is essential, and depends on the individual drug; for many, standardised tests are not available. Mostly this involves, skin prick testing, intradermal testing and challenge. However there are two problems. Firstly, except for the penicillins and general anaesthetic muscle relaxants, tests are often not validated, making interpretation more difficult so these patients need to be concentrated in centres where expertise can be built up from the investigation of large numbers of patients. Secondly, for the non-IgE mediated disorders there are no skin or blood tests and diagnosis (which includes exclusion) is made from history and challenge if indicated. Cross-reacting drugs must be identified so that these can also be excluded. Important also to identify drugs that can safely be given (this is critical when drugs are given intravenously as potential for fatal reactions is greater). In many patients it will be possible to exclude allergy as a cause of their symptoms. Therefore many more patients will need investigation *for* suspected allergy than will be found to *have* allergy.

2.9.3 Management:

Avoid the drug or drugs. Avoid cross-reacting drugs. Identify suitable and safe alternatives.

2.9.4 Patient pathway:

- i. appropriate to manage in primary care by avoiding use of the drug– where the doctor is confident that the reactions are mild and isolated to drugs where alternatives are available which maintain treatment options for patients and control NHS costs.
- ii. diagnosis of cause of multiple and / or severe reactions should be undertaken by an allergy service with specific competencies in drug allergy, expertise and facilities for drug challenge testing. Allergy centres would have this expertise and be able to provide a fully comprehensive investigation
- iii. Dermatologists who specialise in contact dermatitis can help with investigation of certain drug reactions by patch testing. European guidelines exist for this and dermatologists have had input to developing these tests. However this is usually confined to reactions to topical preparations. Patch testing is not usually indicated for systemic reactions. Thus the conditions investigated by an allergist and a dermatologist are distinct.

2.10. Bee and wasp venom allergy

2.10.1 Patient risk and stress:

Reactions may be local (swelling) or systemic – intense rash, breathing difficulty, anaphylaxis with loss of consciousness. A feeling of impending death is common. Death may occur.

2.10.2 Diagnosis:

Accurate diagnosis is essential, especially if immunotherapy contemplated. Interpretation of tests is not straightforward. More complex testing and challenge may be required.

2.10.3 Management:

Risk of exposure can be minimised, but never totally eliminated. Immunotherapy cures up to 95% of patients. Provision of education and rescue medication essential until immunotherapy is completed.

2.10.4 Patient pathway:

- i appropriate to manage local swelling reactions in primary care;
- ii. referral to an allergy service is appropriate for all systemic reactions and where immunotherapy is being considered. Administration of venom immunotherapy should only take

place in an experienced allergy centre. Experience with large numbers of venom allergic patients is important.

2.11 Multiple non-specific symptoms (includes conditions such as CFS, multiple chemical sensitivity and hyperactivity attention deficit syndrome)

2.11.1 Patient risk and stress:

Severe physical and psychological distress both to patients and their families because of difficulty in obtaining diagnosis; patients often feel they are not taken seriously by doctors; allergy – frequently a long list of allergic causes - often wrongly assumed; may be incorrectly diagnosed by alternative (unauthenticated and meaningless) tests. Leads to inappropriate dietary exclusion and other avoidances, sometimes resulting in social isolation and family disruption. Often high cost, in private alternative treatment, to the patient or to PCTs (NHS).

2.11.2 Diagnosis:

Allergy is rarely involved, but specialist expertise and competence in all aspects of allergy is required, in order to over-turn a previous erroneous diagnosis, which the patient is likely to cling to.

2.11.3 Treatment:

Variable and patient specific depending on underlying diagnosis, which may be physical across the medical specialties or psychological; sympathetic management and identification of appropriate consultant for referral on is essential.

2.11.4 Patient pathway:

i. requires referral to an allergy service, when allergy has been suspected. Referral to an allergy centre is recommended.

2.12. Mastocytosis

2.12.1 Patient risk and stress:

High because of anaphylaxis and recurrent severe allergic type reactions (urticaria, angioedema).

2.12.2 Diagnosis:

A rare condition. Opinion required from specialist allergy or dermatologist/haematologist with specific interest in mastocytosis; may also require skin biopsy, bone marrow and other investigations.

2.12.3 Management

Avoidance of triggers; drug therapy; treatment of any underlying condition

2.12.4 Patient Pathway

i Referral essential in all cases as high risk of anaphylaxis. Often associated with anaphylaxis (including venom, where fatal reactions to stings may occur), angioedema, urticaria.

ii. Multidisciplinary approach necessary but important that one physician takes the lead to create expertise in the management of this rare condition. Allergy centres are in a strong position to take on that role.

2.13 Hypereosinophilia

2.13.1 Patient risk and stress:

Variable but potentially high because of risk of severe life threatening disease.

2.13.2 Diagnosis

Opinion required from specialist allergy, dermatologist/respiratory physician or haematologist with specific interest in eosinophilia; may require skin biopsy, bone marrow and other investigations.

2.13.3 Management

Treatment of underlying condition . Avoidance of triggers; drug therapy; treatment of any underlying condition

2.13.4 Patient Pathway

Referral essential in all cases as high risk of significant illness. Multidisciplinary approach necessary but important that one physician takes the lead to avoid confusion and to build up expertise in the management of this unusual group of conditions. Allergy centres are in a strong position to take on that role.

2.14 Eosinophilic Gastrointestinal Disease

2.14.1 Patient risk and stress:

High because of potential for malnutrition

2.14.2 Diagnosis:

Requires search for allergic triggers. May require gastric and oesophageal biopsy

2.14.3 Management:

Avoidance of triggers; drug therapy; surgical treatment if advanced

2.14.4 Patient Pathway:

Opinion from specialist allergist, usually paediatrician

3.0 Referral Pathways for Specific Allergic Conditions in Paediatric Practice

3.1. Anaphylaxis

3.1.1. Patient risk and stress:

Both high – death can be a consequence; fear of death for family; often repeat emergency department attendances; severe psychological stress for family and other carers e.g. teachers when diagnosis is left uncertain or no clear management strategy. Fear of anaphylaxis impedes many everyday activities. Patients often avoiding irrelevant triggers before the diagnosis is made. Co-morbidity is high with eczema, asthma and rhinitis commonly occurring.

3.1.2 Diagnosis:

Complex but in children usually caused by foods, also involves possible drug, latex, venom allergy and physical / idiopathic non-IgE mediated anaphylaxis; asthma often a co-factor but also anaphylaxis often mistaken for asthma. It is crucial to identify cause. Investigation and tests therefore complex and required across a wide range of allergy; challenge testing may be required.

3.1.3. Management:

Avoidance of triggers is essential, and may be complex. Access to rescue therapy and/ or preventative medication necessary for all patients; prescription of medication without accurate identification of cause and a full management package is not appropriate for such a severe and complex disease. Management comes from a multidisciplinary team. Access to a dietician trained in paediatrics and allergy is essential to train families in avoidance and also give a positive message of what can be eaten to ensure adequate nutrition and growth. A paediatric allergy nurse specialist is also important to give the family support and to train school/nursery

staff in trigger avoidance and treatment of emergency reactions. Attention to co-morbid conditions with an allergic component e.g. asthma is vital.

3.1.4. Patient pathway:

- i. Referral to an allergy centre for accurate diagnosis and management is essential in all cases of severe allergic reactions.
- ii. To be effective an allergy centre must have a safe environment for challenge testing and clinical competence in food / drug / latex / venom / idiopathic, physical, intolerance and asthma diagnosis and treatment in children.

3.2. Food allergy/ intolerance

3.2.1 Patient risk and stress:

The peak incidence of food allergy is in infancy; the main burden is in pre-school children. Varies from mild to severe / life threatening; symptoms may be local (rash, mild flexural eczema tingling in the mouth) but more often multiple with asthma, breathlessness, extensive eczema with recurrent skin sepsis, angioedema, urticaria, vomiting and other gut motility disorders. Triggers may vary (and include nuts, egg, milk / dairy produce, fish, seeds, fruit). Natural history or rates of resolution are different for each allergen. Often occurs with asthma, anaphylaxis, angioedema, urticaria, rhinitis and eczema as a multi-system allergic disease. Patient risk may change over time with new allergies developing at different ages and presence and control of asthma changing. The potential for nutritional imbalance and impairment of growth and development is considerable. Once a single food allergy has been identified, without appropriate advice, there is a risk of parents then escalating the perception to other foods thereby creating nutritional compromise. Children with food allergy have reduced quality of life compared to children with other chronic medical conditions e.g. diabetes mellitus. Effective management aims to improve quality of life as well as ensuring safety.

3.2.2 Diagnosis :

Accurate diagnosis is essential. Wrong diagnosis may either protract patient exposure (with potential risk of severe reaction) or lead to an unnecessarily restricted diet; in children this may lead to nutritional deficiency.

3.2.3 Management:

Detailed avoidance advice highlighting areas of risk and education about difficult food avoidance problems; immaculate control of coexisting allergies especially asthma; provide management plan with rescue medication; training of family, carers and teachers/nursery nurses in all aspects. Advice on reintroduction of foods, requires expert help as rates of resolution vary for each allergen and as new food allergies (e.g. to kiwi fruit) with unknown severity spectrums and natural histories emerge, only allergy centres who see large numbers will have sufficient experience to advise, both locally and nationally.

3.2.4 Patient pathway:

- i. appropriate to manage in primary care in older children when:- cause can be isolated easily and is simple; avoidance and reintroduction are straightforward; symptoms are mild and there is no risk of nutritional deficiency from avoidance and there is no complex co-morbidity
- ii Infants and young children with allergy to a single food (e.g. cow's milk) need access to a paediatric allergy service, with a paediatric and allergy trained dietician, to ensure adequate nutrition and plan reintroduction at appropriate time.

iii. Referral to a paediatric allergy centre is essential when there are several possible causes or a novel allergen whose natural history is unknown; when trigger avoidance significantly affects dietary options e.g. in infancy, or avoidance is complex; when symptoms are severe; and/or allergy known to carry risk of a severe reaction (e.g. nut allergy); where there are multiple co-morbid conditions. To be effective, an allergy service must have clinical competence in asthma, anaphylaxis, angioedema and urticaria management and have effective links with dietetics, dermatology, gastro-enterology, respiratory medicine and community teams. Since the range of foods causing allergy are increasing a sufficient volume of work needs to be undertaken to identify and characterise the natural history of novel food allergies and to undertake research. Such a range of skills and resources is only likely to be present in an Allergy Centre

3.3.1 Allergy in eczema,

3.3.1 Patient risk and stress.

Allergic eczema may be a single manifestation, mild to severe in nature; if moderate or severe then this can cause extreme discomfort and pruritus causes disturbed sleep for the child and family, with consequent daytime lethargy. Eczema in childhood is a precursor to asthma and food allergy (the allergic march). Infants and young children may be recommended unnecessary and extensive dietary exclusion (cow's milk, wheat, egg and soya) erroneously without proper allergy diagnosis with significant risk of malnutrition.

3.3.2 Diagnosis :

Patients may benefit from an allergy diagnosis who have eczema which is: - multi system; or where an allergic cause is suspected (e.g. cow's milk protein); or which does not respond to first line treatment and as part of management, the cause (diagnosing or excluding allergy) needs to be investigated. Allergy diagnosis in eczema is complex. Informed trials of dietary exclusion and challenge tests may be required, but require expertise. Detection of persistent sensitisation to egg and a range of other ingestant and inhalant allergens in infants with eczema highlights this group to be at very increased risk of persistent wheeze into adulthood i.e. progression of the allergic march. This facilitates early identification and treatment of this high-risk population.

3.3.3 Management :

Palliative medication is first line; self management based on trigger avoidance requires allergy based diagnosis. Excluding a role for allergy and improving nutrition in some infants.

3.3.4 Patient pathway :

- i. Most eczema is managed in primary care, where allergy diagnosis can add value.
- ii. Referral to a dermatology or general paediatric service is appropriate in single symptom presentations of eczema where allergy is not suspected to play an important role, depending on severity.
- iii Referral to an allergy clinic is recommended when food is suspected as a trigger in eczema, to supervise diagnosis, nutrition, avoidance and reintroduction.
- iv. Referral to a specialist allergy service is recommended when eczema co-exists with asthma and / or rhinitis and/or food allergy; or when eczema is severe; or when nutritional options are limited by avoidance.

3.4. Allergy in asthma

3.4.1 Patient risk and stress :

Risks to children vary from disturbance of normal life activities with reduced exercise tolerance and daytime somnolence caused by disturbed sleep, to recurrent exacerbations requiring time off school and sudden severe / life-threatening attacks with a risk of death. Risk varies between individuals and also within individuals over time. Severe food allergy is occasionally misdiagnosed as asthma and the child is therefore still at risk of exposure to an as yet unidentified allergen. In the presence of asthma, food allergy becomes more severe, especially when asthma is poorly controlled. Co-morbidity with eczema, rhinitis and food allergy is common.

3.4.2 Diagnosis :

Patients can benefit from the identification or exclusion of allergy that have asthma:-which is part of multi system disease, with rhinitis and / or nasal polyps, which is triggered by exposure to known allergens, with co existent food allergy, which is seasonal, and where first line treatments are not effective. Severe asthma may co exist with eczema and / or rhinitis, and in drug and food allergy. Allergy testing can be of value in specific groups. Identification of a food or inhalant allergen sensitisation in wheezy infants and young children identifies those at high risk of persistent wheeze. In children with life threatening and brittle asthma, allergy may be an important trigger. The advent of anti-IgE (and other expensive therapies to follow e.g. anti-TNF) mandates the need for allergy assessment prior to prescription.

3.4.3 Management:

Pharmacological therapy is first line; management based on trigger avoidance (e.g. house dust mite/pet) requires an allergy-based diagnosis. A diagnosis of inhalant allergy in asthma in young children increases risk of wheeze persisting into adulthood. This information may facilitate early intervention to prevent persistent wheeze.

3.4.4 Patient pathway :

- i. Most asthma is managed in primary care, where allergy diagnosis can add value.
- ii. Referral to paediatric secondary care or a tertiary respiratory service is appropriate in single symptom presentations of asthma, depending on severity
- iii. Referral to an allergy service is appropriate when the patient has severe atopic asthma, multi system disease, or when treatments are not effective, or when allergy is suspected (e.g. food allergy, seasonal asthma, house dust mite induced asthma).

3.5 Multi-system allergic disease

3.5.1 Patient risk and stress

Often children with multi-system disease have severe food allergy. This imposes considerable psychological stress due to the high burden of illness and risk of reactions. Many parents view their allergic children as having the sword of Damocles above their heads.

3.5.2 Diagnosis :

Allergy involving skin, lungs, nose and other systems causing risk of severe allergic reactions in many organ systems in an individual child e.g. asthma attacks, eczema exacerbations, worsening rhinitis and risk of anaphylaxis. Often complex and requires specialist knowledge of the underlying role of allergy in multi-organ disease. Patients will benefit from the inclusion or exclusion of the role and nature of allergy for each organ system.

3.5.3 Management : A comprehensive approach to management is required to treat the underlying components of allergy in each organ system. Asthma, rhinitis, eczema, food allergy and anaphylaxis will need attention in each child.

3.5.4 Patient pathway :

Referral to an allergy centre.

3.6. Rhinitis and Allergic Conjunctivitis

3.6.1 Patient risk and stress

Rhinitis is under-recognised and its influences on daily activities (e.g. lethargy) and other allergic disease (e.g. asthma) are often overlooked. Varies from mild to severely disruptive of everyday life. Children suffer with poor sleep, daytime lethargy and impaired examination performance,. Symptoms may be confined to the nose and the eyes; but commonly associated with asthma and eczema. Allergic rhinitis increases risk of persistent asthma. May be associated with nasal polyps, which cause severe morbidity. Triggers may be pollen, animals, dust mite. May be seasonal or perennial.

3.6.2 Diagnosis :

Mostly straightforward identification of triggers through case history and skin prick testing. Allergic cause of symptoms needs to be confirmed or ruled out. Identification of rhinitis in children with asthma is important as correct management can improve asthma control. Furthermore an allergy assessment of children with allergic rhinitis will identify future risk of asthma.

3.6.3 Management : First line medication of isolated symptoms is often sufficient. Immunotherapy can reduce symptoms by 70%.

3.6.4 Patient pathway :

- i. most patients are dealt with appropriately through self medication or in primary or secondary care.
- ii. where severe symptoms are not being controlled or where immunotherapy is required, referral to an allergy service should be considered, or where allergic cause needs to be confirmed or refuted and this cannot be done in primary or secondary care. Referral to ENT should be considered where surgery for polyps is appropriate. Referral for an ophthalmological opinion may be required in severe cases of keratoconjunctivitis.

3.7. Drug allergy (antibiotic allergy; general or local anaesthetic allergy; and NSAID sensitivity; opioid intolerance; others).

3.7.1. Patient risk and stress :

Varies between patients from mild to life threatening reactions. Where symptoms are mild (certain types of rash), and if therapeutic alternatives are available, appropriate simply to avoid prescribing the drug. (However, substantial NHS cost are involved when, for example, patients are labelled as allergic to penicillin, and prescribed alternative antibiotics without proper testing). Need for accurate diagnosis increases with severity of reaction (e.g. rash and angioedema, anaphylaxis, rash causing severe illness). Complexity of the illness and the diagnosis is increased because of cross reaction between drugs.

3.7.2. Diagnosis:

When this is required, can be complex and often involves drug challenge. Accurate diagnosis is essential, and depends on the individual drug; for many, standardised tests are not available. Cross reacting drugs must be identified so these can also be excluded. Important also to identify

drugs that can safely be given (this is critical when drugs are given intravenously as potential for fatal reactions is greater).

3.7.3 Management :

Avoid the drug or drugs.

3.7.4 Patient pathway :

- i. appropriate to manage in primary care by avoiding use of the drug– where reactions are mild and isolated to drugs where alternatives are available which maintain treatment options for patients and control costs.
- ii. diagnosis of cause of multiple and / or severe reactions (e.g. general anaesthetics) / or where choices of alternative drugs are limited or complex (e.g. cystic fibrosis) should be undertaken by a paediatric allergy service with specific competencies in drug allergy, expertise and facilities for drug challenge testing and sufficient volume of work to undertake research to improve drug allergy identification and management. Allergy Centres and some Allergy Clinics would have this expertise.

3.8. Bee and wasp allergy

3.8.1 Patient risk and stress :

Reactions may be local (swelling) or systemic – intense rash, breathing difficulty, anaphylaxis with loss of consciousness. Death may occur. However, the prognosis is better in children than adults.

3.8.2 Diagnosis :

Accurate diagnosis is essential, especially if immunotherapy contemplated. Interpretation of tests is not straightforward. More complex testing and challenge may be required.

3.8.3 Management :

Risk of exposure can be minimised, but never totally eliminated. Immunotherapy cures about 95% of patients. Provision of education and rescue medication

3.8.4 Patient pathway :

- i appropriate to manage local swelling reactions in primary care;
- ii. Referral to an allergy service is appropriate for all generalised or large local reactions and where immunotherapy is being considered. Administration of venom immunotherapy should only take place in an Allergy Centre.

3.9 Latex allergy

3.9.1 Patient risk and stress :

Variable severity but lack of understanding amongst hospital staff exaggerates risk and creates fear and anxiety.

3.9.2 Diagnosis :

Clinical skills and experience paramount, ability to perform and interpret allergy tests

3.9.3 Management :avoidance;

This requires planned management during medical interventions (e.g. dentist or surgery); emergency treatment plans for inadvertent exposure; control of asthma, eczema and management of associated food allergies. The latter requires very careful assessment to reduce un-necessary avoidance diets.

3.9.4 Patient pathway :

- i. referral to an allergy service for all patients

ii. to be effective allergy service requires competence in latex and food allergy, asthma and eczema. Such competence will be found in allergy centres and some allergy clinics.

3.10 Urticaria and angioedema

3.10.1 Patient risk and stress :

In children usually a single acute episode but may be chronic and severe. Impaired quality of life due to intense itching and disfigurement by rash. Poor sleep, impaired concentration and loss of time from school over long periods. Suspected allergic cause leads to avoidance often of foods, without diagnosis. Distress due to constant search for a cause, where usually none is found. In acute urticaria, families usually avoiding a particular food without allergy diagnosis, unnecessarily.

3.10.2 Diagnosis :

Requires ability to interpret history and to perform allergy tests as indicated to exclude an allergic cause and provide reassurance.

3.10.3 Management :

Drug treatment; avoidance when trigger confirmed

3.10.4 Patient pathway

i. simple acute urticaria dealt with in primary care
ii. referral to allergy service when allergy suspected, in order to exclude or confirm allergy; when co existing angioedema; with angioedema with tongue swelling or other airway involvement; when difficult to control, when symptoms are severe. The allergy service requires skills in diagnosis (and exclusion) of food and drug allergy and knowledge of physical triggers to exacerbations of chronic urticaria. Allergy centres, the majority of allergy clinics and organ-based clinics with a dermatology background should have this expertise.

3.11 Multiple non specific symptoms [note: this differs from multi-system allergic disease]

3.11.1 Patient risk and stress :

Severe psychological distress because of difficulty in obtaining diagnosis; patients often feel they are not taken seriously by doctors; allergy often wrongly assumed; may have been diagnosed by alternative testing, many of which have been shown to be totally erroneous. Leads to inappropriate dietary exclusion and other avoidances, sometimes resulting in social isolation and family disruption. Often high cost, in private alternative treatment, to the patient or to PCTs (NHS). ADHD is currently a common cause of referral to allergy services and constitutes a common problem, with prevalence rates between 5 and 15% depending on definitions.

3.11.2 Diagnosis :

Allergy is rarely involved, but specialist expertise and competence in all aspects of allergy is required, in order to over-turn a previous erroneous diagnosis, to which the parents are likely to cling.

3.11.3 Management:

Variable and patient specific depending on underlying diagnosis, which may be physical or psychological; sympathetic management and identification of appropriate consultant for referral on is essential. This requires close collaboration between the child and adolescent psychiatry and allergy services to ensure the child is redirected to more appropriate therapy.

3.11.1 Patient pathway :

i. requires referral to an allergy service, when allergy has been implicated. Referral to an allergy centre is recommended.

3.12. Mastocytosis

3.12.1 Patient risk and stress:

High because of anaphylaxis and recurrent severe allergic type reactions (urticaria, angioedema) although prognosis is usually benign in childhood

3.12.2 Diagnosis

Opinion required from specialist allergy or dermatologist with specific interest in mastocytosis; may also require skin biopsy, bone marrow and other investigations.

3.12.4 Management

avoidance of triggers; drug therapy; treatment of any underlying condition

3.12.4 Patient Pathway

Allergy centre advised, but prognosis good when it presents in infancy.

3.13 Other Gastrointestinal disease

3.13.1 Patient risk and stress

Protein enteropathies can cause life threatening reactions as well as pain and psychological stress. Gastro-oesophageal reflux causes failure to thrive in young babies and debilitating vomiting, diarrhoea or constipation occur in food intolerance and eosinophilic enteropathy.

3.13.2 Diagnosis

This is complex and but often overlooked or not actively sought, especially in gastro-oesophageal reflux where it is often assumed it will resolve spontaneously. Correct diagnosis requires expert assessment by paediatric allergist working in collaboration with paediatric gastroenterologist and dieticians. Invasive investigation (e.g. endoscopy) is often required.

3.13.3 Management

Complex requiring expert help from paediatric allergists and often gastroenterologists

3.13.4 Patient pathway

Referral to allergy centre with paediatric gastroenterology

Section 2: Model of Service

1.0 Current Model of Service

1.1.Introduction

A set of referral pathways as described above only make sense in the context of a model of service. The current service for the care of patients with allergic disease within the NHS has grown up in an *ad hoc* manner, with considerable variability in the provision of specialist services depending on geography and local attitudes. The variable quality and quantity of specialist advice available to a patient with allergic disease is a good example of the postcode lottery that is found elsewhere in the NHS. Much of this is due to a paucity of specialists with appropriate training and expertise, the lack of central direction and agreed service models with their associated patient journeys and inadequate resources for allergy

The mainstay of allergy care for mild disease is (and should remain) in the primary sector. Patients with a clear diagnosis and mild but persistent symptoms can be readily managed in primary care without referral. Where there is diagnostic doubt or moderate to severe disease (including patients with mild symptoms where there is future risk, for example nut allergy), referral for specialist consultation is advised. In most cases once the diagnosis and a treatment plan is established continuing care will be by the GP.

If referral for a specialist opinion is considered by the GP to be necessary there are potentially a number of different options depending on local service provision which varies widely. Many GPs have no comprehensive allergy service to which to refer. The types of service potentially available can be described as follows:

Organ Based Service: Allergy service provided by organ-based specialist (respiratory, dermatology, ENT, gastroenterology) with expertise and a practice largely restricted to patients with allergic disease related to that organ.

Allergy Clinics: Allergy service provided which sees patients with systemic allergy but is limited in scope and expertise evidenced by provision of a limited service by comparison with specialist service definition set no 17 (for example not seeing patients with organ based conditions such as asthma or rhinitis or not having drug diagnostic tests or challenge). These services will encompass a wide range of constituents and vary widely in capacity, expertise and facilities from those approaching allergy centre level services to those seeing a restricted subset of general allergy. Most are small but some services may have higher capacity, often limited by funding or staffing constraints or lack of suitable facilities to offer specialist allergy components (e.g. for immunotherapy, drug and food challenge, diagnostic facilities for co-existent asthma and rhinitis). Most consultants providing these allergy clinics have a primary role/appointment in another specialty.

Allergy Centres: A comprehensive service in the sense of providing the full range of specialised allergy services commensurate with specialist service definition 17 with high capacity and expertise. Ability to diagnose and manage all forms of allergic disease at all levels of complexity and severity. Allergy would be the main role of the consultants providing the service. There would usually be adult and paediatric allergists and specialist allergy nurses and dieticians. The centre should also have an extended role in providing a number of additional services. These would include outreach services to the local community with near patient diagnosis and management, an educational role for primary and

secondary care, research, training for F2 trainees, SpRs and medical care practitioners, guideline setting, clinical trials and championing the cause of the specialty at a local and national level. The centre acts as hub to support a network of allergy providers including organ based specialists, emergency physicians, general paediatricians with an interest in allergy and specialist community based care.

1.1 Analysis of Allergy Services on the BSACI Website

Some insight into the current state of allergy services in the UK can be gained from an analysis of the BSACI list of clinics published on its website. This is as far as we are aware the only comprehensive source of information on allergy services in the UK. An analysis of the website gives a snapshot of what types of services are currently available to GPs (including Northern Ireland). A subsequent analysis of this data follows. The data on the clinics is self-described and not crosschecked by the BSACI. It therefore represents how the service providers currently perceive their own services.

1.1.1 Types of Clinics

There are currently registered on the BSACI website eighteen services which would fit the description of an Organ Based Service. Ten of these are respiratory, five ENT, two dermatology and one ophthalmology. This reflects the pattern of consultant membership of the BSACI. Presumably these are the organ-based specialists with an interest in allergy. Some organ-based specialists will have had a degree of training in the allergic basis of the conditions affecting their organ of interest. However not all chest and dermatology units will have access to facilities for skin prick testing or will undertake an allergy assessment where relevant to the condition being seen. However the extent of the interest and expertise in allergy in these units cannot be assessed from our data.

Thirty-six sites on the BSACI website fit the above description of 'Allergy Clinics' seeing adult patients. As would be expected in a situation where until recently there has been no 'allergy' training programme the background of the specialists providing the service is very varied. Sixteen clinics are run by physicians who regard themselves primarily as allergists (2 allergy alone, 8 allergy with a respiratory background, 1 allergy and dermatology, 4 allergy with clinical immunology support and 1 respiratory and anaesthetics). 20 of the clinics are provided by practitioners who primarily regard themselves as immunologists (9 clinical immunology alone, five clinical immunology and allergy, three clinical immunology and respiratory, 2 clinical immunology and ENT, 1 clinical immunology and anaesthetics). As might be predicted the service offered by these clinics is also very varied. Of the 36 clinics listed two thirds see children as well as adults and two thirds offer immunotherapy. The number of consultants involved ranges from 1 to 4 and the number of outpatient clinics a week from six in which only patients with allergic disease are seen to one clinic in which allergy patients are mixed with other conditions. Twenty-five of the sites are south of the Trent. There is effectively one site each in Wales (there is also a paediatric site), Scotland and Northern Ireland.

Ten of the 18 Organ Based Services offer services for children. Only one of these involve a paediatrician. Twenty-six of the thirty-six Allergy Clinics see children. Of these 8 involve a paediatrician. In these mixed adult and paediatric clinics it has not been possible to separate the numbers of adults versus children seen so the capacity numbers given below include both adults and children. In addition to the Allergy Clinics described above there are 22 paediatric only allergy services. 14 of these are run by general paediatricians with an interest, 4 by paediatric allergists, 3 by paediatric immunologists and 2 by paediatric respiratory sub-specialists.

1.1.2 Capacity of the Clinics

It is difficult to extract precise numbers of patients seen in these clinics from the information that has been provided to the BSACI as this is provided in the form of the number of outpatient clinics each week. We are currently updating our website with additional information which will provide a more accurate assessment of numbers of patients seen. We have previously undertaken an analysis of capacity for the Health Select Committee report in which we used the number of out patient sessions(clinics) recorded on the website ('An NHS Plan for Allergy: Making a Start' [6]). From these data we have defined a figure of total capacity of about fifty thousand new patients a year. Here in this more detailed analysis we have used the number of outpatient clinics undertaken. For the purposes of this paper we have assumed that a consultant in a clinic devoted to allergy will see 5 new patients and undertake 45 clinics a year. Where the clinics see other types of patients mixed with allergy we have assumed 50% of the patients will have allergic disease. These assumptions have been validated by cross checking our numbers with the recent survey of clinical immunology clinics [7]. While there was some variation for individual clinics the overall numbers were remarkably similar, especially when taking into account that several of the clinics in the clinical immunology survey did not clearly distinguish patients with allergy from those with immune deficiency and other immunological disorders. Based on these figures the Organ Based Services have a capacity of 80 new patients a week (3,500 per year), the 'Allergy' Based services 250 week (11,250), and the 'Clinical Immunology' based services 210 week (9,450). The Paediatric Only Services have a capacity of 150 new patients a week (6750). Total capacity is therefore in the region of thirty thousand adults and children a year.

What is most striking about these figures is the gap between current capacity which is in the region of 30, 000 to 50,000 patients per week and the more than 3.5 million patients who would benefit from an assessment by a specialist with expertise in allergy [1]. While it is acknowledged that these figures are an estimate on an incomplete dataset but they give a minimum indicator of current capacity. For example from trust activity data Guy's Hospital sees 5,000 allergy patients and Addenbrookes hospital 5,400 allergy patients per annum: in excess of 10,000 patients in 2 specialist allergy centres alone. The main issue is that potential capacity to see patients with severe allergic disease is larger, and can be reached by developing existing centres utilising the model in appendix 1

1.1.3 Type of Patients Seen and Quality of Service Offered

The BSACI has no firm data on the reasons for referral of patients to the services described on their web site. It is likely that this will vary depending on the type of service. Organ Based Services will see largely conditions relevant to that organ. We can also glean little from the survey about the quality of the services offered. Thirty-seven of the services appear to be single handed which is regarded as a sign of vulnerability in terms of clinical governance; and most of these have a primary role in another specialty. Generally speaking it might be expected that a service with consultants seeing large numbers of allergy patients and offering expertise and resources in the full range of diagnostic and treatment services would be providing a better quality of service than a single handed consultant seeing allergy as part of a range of other conditions. Forty-three services currently appear to be able to see no more than 200 new patients a year.

This analysis demonstrates that the current secondary care sector for allergy is made up of a very heterogeneous mix of service provision in terms of background of the specialists involved, the numbers of outpatient clinics undertaken and the types of patients seen. There are currently about eight relatively well-resourced general adult and paediatric allergy clinics that currently approximate to allergy centres

as defined in Appendix 1. While each type of service makes a valuable contribution to the management of allergic disease as a whole, the service is fragmented and geographically unequal. In many areas of the UK the NHS allergy service lacks leadership and co-ordination resulting in limited capacity and sub-optimal quality. This means the GP when requiring specialist support is frequently faced with an often confusing and limited choice of referral options. When combined with the generally poor knowledge of allergy in primary care this can make the patient journey inefficient, slow, frustrating and potentially puts the patient at risk.

2.0 Future Model of Service

2.1 Primary Care

The primary care aspects of allergic disease will be discussed in a Primary Care paper provided for a discussion meeting with the Primary Care leadership; and in the 'Nature and Extent of Allergy' [1]. It is generally agreed that the majority of allergy care should be provided by the primary care sector. 'Nature and Extent' gives estimates of the workload that would have to be dealt with in Primary Care: 20 million presentations of disease which could be treated symptomatically (some of these will self-treat) and 5 million presentations of disease where an allergy diagnosis is needed. In addition primary care would provide ongoing care for those diagnosed in allergy clinics. However the conditions would have to be created in which Primary Care could develop the capacity and competencies to deal with this workload. Proper referral guidance based on local pathways is essential to effectively develop appropriate care for allergic disease. As with other common chronic problems such as COPD, asthma and diabetes there needs to be a mechanism for screening all patients for significant allergic disease in order to facilitate assessment of which level of care is required. Quality standards for allergic disease in primary care are also required. One problem we have encountered is that the level of understanding of allergy in primary care is poor and the diagnostic facilities (particularly skin prick testing) and expertise to make an accurate diagnosis are usually not available.

2.2 Need for Allergy Centres

Even if Primary Care services could be developed to meet this demand, there remains a substantial number of patients with disease requiring referral. 'Nature and Extent' estimates the number of these to be in excess of 3.5 million and up to 7 million people. They include disorders which are potentially severe, where diagnosis is more difficult and where there is high co-morbidity. These need referral to an allergy centre or a secondary care specialist with experience in managing allergic disease.

High quality allergy care in the primary sector requires the establishment of a geographically comprehensive, well-maintained educational platform that will reach out to all GP's and their support staff. This in turn requires a UK wide network of secondary care providers with the time, expertise and commitment to provide that platform. The current mix of organ based and general allergy services will always be a valuable part of UK allergy provision, essential to meet present and future demand. **What is largely lacking in the current service model is a fully resourced network of Allergy Centres.** Allergy Centres are an essential component of the service model, for as well as providing increased capacity and effectiveness, and a tertiary referral service, they will provide co-ordination and leadership both locally and nationally for clinical services and allergy R&D. Leadership is essential to first set and then audit standards of allergy care including the establishment of local and national guidelines, to lobby for improved local services, to provide a local hub for education for undergraduates, primary care and other secondary care providers, They will be key to training the

initial cadre of future whole time consultant allergists and to undertake research into causes of allergy and new approaches to management. **It cannot be emphasised enough that a high quality primary care service will simply not happen without a geographically comprehensive network of Allergy services meeting all the criteria for centre status. The central point of this document is that the creation of such a network of centres is the most cost-effective and efficient way to improve allergy services in the next 5 to 10 years.** As a basic minimum the BSACI anticipate a need for one allergy centre at each teaching hospital.

2.3 Definitions of Types of Allergy Service.

The service specification for an Allergy Centre is described in Appendix 1. The difference between an Allergy Centre and an Allergy Clinic is essentially one of specialism, focus and resources. Centres provide facilities for high level tertiary referral, and lead in training and R&D as part of their core function. As noted above there are perhaps only a few services that currently meet all the criteria for an Allergy Centre as defined in the Appendix. A number of services that currently meet the definition of Allergy Clinics offer extended roles in education and local support to GPs and secondary, but not tertiary, care similar to that expected of Allergy Centres. Some will be co-localised with laboratory allergy services when provided by Clinical Immunologists. Some of these services might wish to develop into Allergy Centres with time to populate an equitable geographical access to extended allergy services encompassing the full range of allergic disease. It is critical to stress that it is the level and nature of service being provided that defines the type of service and not the background of the consultant providing it, provided that they have the appropriate level of training and experience. Physicians with a background in respiratory medicine or immunology could develop an Allergy Centre if their career ambitions were in allergy and local needs supported such a development. Conversely consultant allergists could be running Allergy Clinics if they do not have the resources to achieve the service specifications of a centre. Although in the longer term it would be anticipated that all allergy centres will be staffed by consultants with a certificate of competence in allergy, development of a geographically uniform network of allergy centres will require allergy clinics staffed by consultants with backgrounds in immunology, respiratory medicine and other disciplines to expand into allergy centres and this multidisciplinary model of service provision would not exclude a service from centre status provided allergy was the primary and main role and staff had the appropriate level of training and expertise.

2.4 Implementation of the Model

If the model described above is accepted as a way forward for a high quality NHS allergy service then it will need to be implemented in a planned and structured manner. Crucially it will need central direction. If implementation relies on local action for delivery it will not happen. GPs with their limited understanding of allergy will not press for change, as it is erroneously perceived as a low priority for PCTs compared to their many competing challenges and there are few local champions in secondary care to initiate and drive change even though national statistics and patient testimony identifies a major unmet clinical need. A survey of all PCTs in England confirmed that developing allergy services was not a priority or part of their plans (provided as an Annex to the Primary Care paper [2]). The currently small number of allergy trainees also means that implementation will need to be a staged process. It is likely that full implementation of the initial phase will take up to five years. It has been suggested that it will be difficult to recruit trainees into allergy. The BSACI does not support this view. Allergy is an attractive specialty for someone who wishes to do hospital medicine but wishes to have the flexibility that comes with a predominantly ambulatory out patient based specialty. We have had no difficulty in recruiting SpRs to the current allergy national training numbers (NTNs).

2.4.1 Stage 1:

Identification of locations where allergy centres might be established by an open and transparent process based on an accreditation process. As mentioned above these are likely to be based on teaching hospitals with an existing allergy service which will give uniform cover to the UK. Achievable service standards will need to be agreed with appropriate specialty stakeholders. These would be linked to an open and accountable accreditation process and incrementally tightened with time to promote service development and continuous quality improvement. Additional centrally funded SpR training posts in adult and paediatric Allergy will be an essential part of the first stage of the process. There is capacity in existing allergy centres to accommodate these training posts.

2.4.2 Stage 2:

Planned expansion of allergy services with centrally directed investment and manpower planning. Commissioning of local allergy centres by PCT against defined service standards. This would include creation of sufficient allergy training posts to support future consultant expansion in Allergy in combination with an expansion of appropriate consultant posts as trainees become available. This would be an organic process with allocated centres bidding for funds as and when appropriate.

An immediate impact with minimal additional cost could be obtained by transferring unfilled centrally funded SpR posts in other specialties to allergy.

Figure 1:The referral pathways set guidelines for when patients need referral for a specialist opinion and the type of service that would be equipped to deal most effectively with the problem. In all cases an allergy centre would be able to optimally diagnose and treat any allergy related problem. In some cases either organ based or general allergy clinics that do not meet the specifications of an allergy centre may be able to deal with the problem depending on the local capacity and expertise. The Allergy Centres also act as a tertiary referral point for Allergy Clinics and Organ Based Services as well as interacting with the local GPs to provide an educational and outreach platform.

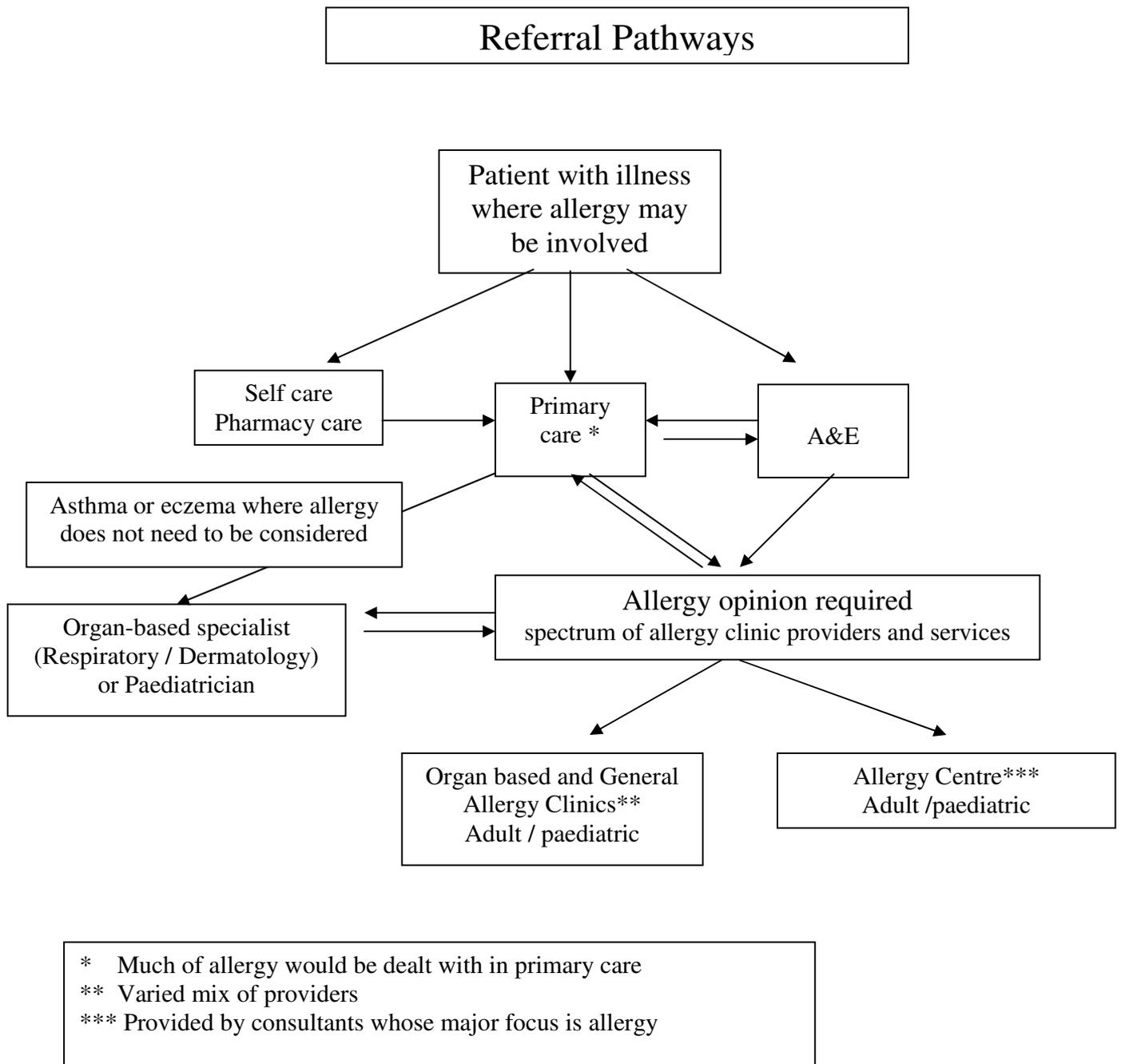
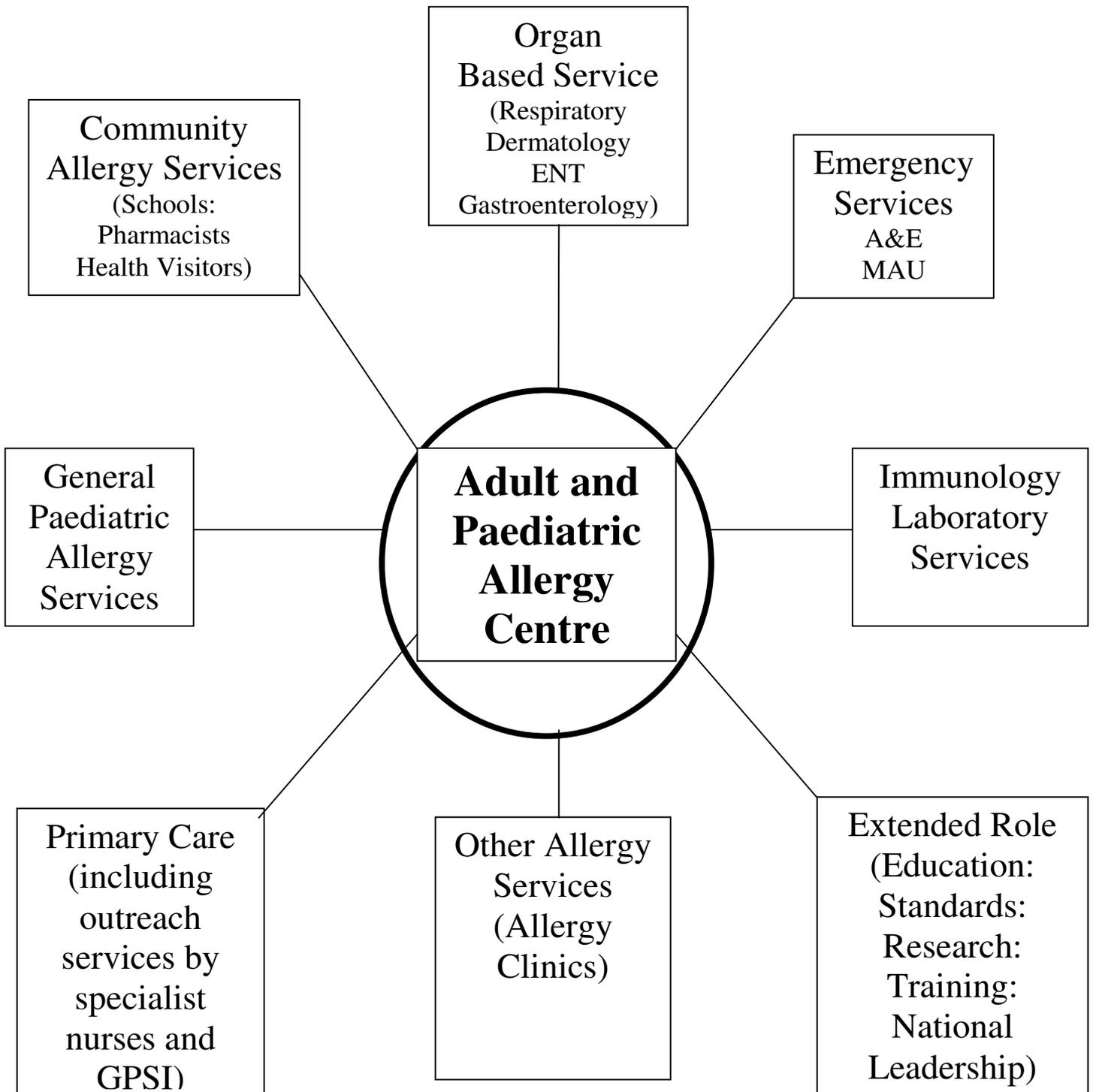


Figure 2: The Networking Role of Allergy Centres

Allergy Centres as well as providing increased capacity for straightforward secondary allergy referrals and a tertiary referral service for complex allergy also form the hub of a network of allergy services in the region in which they operate. This includes networking with other secondary care providers, support for community allergy services, liaison with emergency services to make sure acute allergy emergencies are followed up and support for primary care based services. This could include outreach services by specialist nurses for locally based consultations. They will also offer an extended role to strengthen allergy services both at a local, regional and national level. They are therefore a fundamental component of our model. Without the hub the network fails. This component is currently lacking in many parts of the UK.



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Appendix

Specifications of an Allergy Centre

Referrals

- *Types of patients seen.* All patients with suspected allergic disease based on the Specialised Services Definition Number 17 would be seen. Both adult and paediatric patients would be seen where locally possible and where appropriate expertise available but provision of adult-only or paediatric only would not disbar from centre status. The centre requires to have the necessary skills to manage all types of allergic disease in the specialist service definition. As well as seeing all types of secondary care referrals, allergy centres will have a particular focus on patients with multi-system allergy; severe allergy; disorders with a risk of severe reactions; allergies where diagnosis or diagnostic tests are complex to interpret or not well validated; food, drug, latex and venom allergy; challenge testing and immunotherapy.
- *Waiting Times:* For routine cases the service would at least fulfil the national targets set by government for outpatient waiting times. Capacity to see urgent referrals in a timely manner (e.g. anaphylaxis) is paramount. Mechanisms for identifying and managing patients with severe allergic disease presenting to the host institution (i.e. those seen in A&E with anaphylaxis) or in patients with drug allergy will be in place.

Staffing of Service

- *Consultants:* Two FTE consultant adult allergists or equivalent and/or two FTE paediatric allergists or equivalent. (The definition of an allergist is someone with specialty expertise in allergy who spends the majority of their time involved in managing patients with allergy and who has the necessary expertise to see all types of allergic disease and maintains CPD in these areas). In the case of academic allergists they would be counted as 0.5FTE equivalent where they spend the majority of their clinical time involved in allergy care and their research is allergy related. While it is difficult to envisage centres existing in the long-term without a substantial component of full-time allergists, initial criteria have to be more flexible to allow incremental service development. The centre as a whole should have the relevant expertise to cover the entire service repertoire and meet the workload safely.
- *Allergy nurse specialists.* 2 FTE adult allergy nurse specialists and 2 FTE paediatric allergy nurses. This could include an allergy nurse consultant. An allergy nurse specialist is defined as a nurse who spends the majority of their time involved in allergic disease and is competent to deal with the full range of allergic diseases and maintains that competence through relevant CPD. Allergy nurse specialists may specialize in particular organ-based manifestations but the centre as a whole should have the relevant expertise to cover the entire service repertoire and meet the workload safely.
- *Dietician:* A FTE allergy specialist dietician with expertise in the management of food allergy in children and/or adults

- *Pharmacy:* A pharmacist with allergy expertise and access to facilities for making preparations for drug challenges or an equivalent mechanism to achieve safe challenges
- *Administrative Support:* Dedicated secretarial support for each consultant is essential as well as support staff to run the clinics
- *CPD:* All clinical staff within an Allergy Centre would be expected to be members of a professional organisation which provides recognized CPD in allergic disease such as the BSACI EAACI, AAAAI or others and to maintain a strong record in allergy CPD attending the relevant annual meeting most years and an international meeting at least once every other year on average.

Services Provided

- A largely outpatient / day case service for all patients with suspected allergic disease commensurate with specialist service definition 17. Clinics would be dedicated to allergy and patients with non-allergic conditions would not be seen in those clinics
- A tertiary referral service for complex allergy patients in the region
- A secondary service for other allergy patients in the strategic health authority
- An in-patient consultation service with patients seen in a timely manner
- Expertise and facilities for the diagnosis and management of drug allergy including antibiotic allergy, general and local anaesthetic allergy, aspirin, NSAID sensitivity and multiple drug allergy syndrome. Skin prick, intradermal and challenge tests
- Expertise and facilities for the diagnosis and management of food allergy including single and double blind controlled food challenges
- Day case facilities for challenges and complex investigation
- Skin prick testing
- Aerobiology including assessment of levels of home allergens where relevant and essential to the patients management
- Admission service for assessment for patients with severe allergy
- Full immunotherapy service
- Access to a full respiratory physiology service (Pc20, full RFT's, induced sputum, exhaled nitric oxide, hyperventilation assessment)
- Comprehensive systems for anaphylaxis management, treatment plans, school training, liaison with community paediatric team, protocols etc

- Documentation for procedure and recording of specialist investigation, challenge testing etc
- Comprehensive literature, patient information, 'to whom it may concern' letters for defined diseases e.g. latex allergy; drug allergy, general anaesthetic anaphylaxis.
- Close liaison with dermatology colleagues for easy access to patch testing facilities or participation in the service
- Close liaison with gastroenterology colleagues for easy access to gastroenterological investigations
- Joint ENT/allergy clinic for difficult upper airway problems
- Access to comprehensive immunology laboratory diagnostic services
- Full quality policy with document control and authorised policies, guidelines and procedures
 - Outreach service to GPs for near patient diagnosis and management
 - Agreed referral pathways with all stakeholders
 - Participation in a transparent accreditation process against agreed service standards

Capacity of Service

An allergy centre would be expected to see a relatively large number of patients and offer appropriate number of challenges to be able to maintain the experience to provide a comprehensive service as well as support training and research opportunities. It is estimated that each consultant would see 4 new patients and 6 follow up patients per clinic and do four OPD clinics and one challenge clinic per week involving two challenges (drug or food). Based on a 42 week year this would mean each service could see over 1500 new and 2000 follow up adults and the same number of children per year.

An Allergy centre would therefore see:

- A minimum of 1000 new and 1000 follow up adults and the same number of children per 2 WTE consultants. This would equate to 500 new-patient referrals per WTE consultant per year
- A minimum of 100 drug and food challenges each for adults and children per year as needed clinically
- A large immunotherapy service for patients with venom allergy and severe rhinitis with a major dedicated immunotherapy clinic each week

All consultations will be coded as Allergy

Facilities

- Adequate outpatient facilities
- Access to Day Care facilities
- Access to in patient beds with 24 hour cover
- Resuscitation equipment and trained staff
- Offices for consultant, nursing staff and trainees

Audit

- There would be an active audit programme with a minimum of two service audits in allergy per year

Education

- A planned programme of education for trainees in both allergy, immunology and relevant organ based disciplines (one regional meeting a year)
- A planned programme of education for allergy stakeholders in the region (two meetings per year to discuss interesting cases/ new developments)
- A planned programme of primary care orientated seminars (two per year)

Training

- The centres would train new Specialist Allergists. At least two SpRs in adult allergy (allergy CCT) and two paediatric allergy trainees would eventually be based in each centre. The centre would offer training to F2 trainees, secondary care nurses and other secondary care providers as appropriate including SpRs from other specialties (or general paediatrics) to fulfil the allergy components of their curricula

Research

Most centre-level services would support an active programme of research in allergic disease. This could be into basic mechanisms or clinically orientated research into new treatments, diagnostics or service delivery models. For centres with academic appointees it would be expected that at least one external grant and one high impact peer reviewed paper would be held/published by the service each year.

Networking Role

The service would interact constructively with other allergy providers in the region co-ordinating policy on guidelines, standards of care, patterns of referral and other aspects of the service. This would include close liaison with organ-based specialists with an interest as well as

close interaction with clinical immunologists both as providers of allergy care and in their role of running the laboratory allergy service. There would also be an important outreach role in primary care with the possibility of PCT based clinics and a community based skin prick testing service complemented by a strong educational message. This service might well be led by a specialist allergy nurse (or nurse consultant or clinical assistant/GPSI). There would also be an educational programme aimed at community pharmacists and good media relations to promote a positive and accurate patient focussed educational message.

Summary

The key requirements of an allergy centre are therefore:

- Comprehensive allergy practice including particular expertise in the more severe and difficult allergy, multi-system allergy and disorders requiring more complex diagnostic skills or procedures
- A referral pattern commensurate with Specialist Service Definition No 17 for Allergy with capacity for seeing large numbers of patients coded as Allergy and high quality facilities for challenge and immunotherapy.
- A well resourced service staffed by a minimum of 2-WTE consultants or equivalent with relevant skills and expertise, supported by skilled, trained PAMS with adequate administrative and management support.
- Evidence-based clinical practice governed by appropriate guidelines and protocols.
- An extended leadership role involving standard setting, training, education, research and outreach interaction with primary care