



# Developing allergy services in the North West of England

Lessons Learnt

**Authors:**

Louise Sinnott  
North West Allergy Project Manager

Roy Dudley-Southern MBE,  
Associate Director (Strategy)

(North West Specialised Commissioning Group)



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*The images within this report provide an illustration of some common allergens and are not representative of the entire range of allergic disease in the UK.*

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# Foreword



Despite large numbers of people believing they have an allergic root to their health problems, allergy services in the UK have seriously lagged behind our European neighbours. Many of those with such a belief do not, in fact, have evidence of an allergy, while many others with serious and potentially life-threatening allergies go undiagnosed. Thus the tightrope of allergy continues for patients despite medical science knowing ways to accurately diagnose and effectively manage many allergic conditions.

Behind this lie several factors, one being a lack of general postgraduate training in allergic disease and another being a mushrooming of over the counter allergy 'diagnostic kits' that are not evidence-based.

The importance of allergy in the everyday lives of people, the role of the accurate diagnosis and the new technologies of desensitisation, all offer hope of a revolution in care. Allergies have not received the attention in healthcare that they deserve, resulting in a workforce shortage of those with specialist training. Allergies can cripple people's lives and – when misdiagnosed – can cost them their life itself.

In the House of Lords report on Allergy (2007) we suggested models of care that could be adapted at a local level to harness clinical interests and coordinate services provided by such clinical teams.

A major part of our report was to advocate that funding be provided for a pilot to undertake service reorganisation and to evaluate it. Now that radical NHS changes are imminent the report is even more important as the findings on specialist provision and the potential for perverse incentives in tariff payments have implications for many specialist services, far beyond allergy.

This report is the long-awaited culmination of those efforts. The North West was chosen as the area in which a new service model should be evaluated. This report highlights the lessons learnt and the implications for other services. The eyes of the allergy community have been on the North West during this pilot – this report is eagerly awaited.

A handwritten signature in black ink that reads "Ilora Finlay".

**Ilora Finlay**

*Professor Baroness Finlay of Llandaff FRCP, FRCGP, Chair of House of Lords Select Committee on Science and Technology report 'Allergy'*



## Executive summary

Allergy is the most common disease of our time with almost one third of the population having an allergy of some kind.

However, NHS capacity and capability to accurately diagnose, manage and treat allergic disease outside specialist centres is lacking. This clinical knowledge and skills gap earlier in the patient pathway means that, for many patients, optimal advice is not given and inappropriate referrals are made to a bewildering range of services. Where specialist centres exist, they operate mostly in isolation, leaving them unsupported and vulnerable without robust governance arrangements.

This report sets out the history and development of a Department of Health pilot project to improve NHS allergy services. It also describes the lessons learnt and the changes to allergy services in the North West of England which have resulted from this work. The project was undertaken by the North West Specialised Commissioning Group (NWSCG), acting on behalf of the North West Strategic Health Authority (SHA) and the 24 primary care trusts in the region. It effectively started in February 2009 and ran until January 2011, although some aspects remain to be completed.

The project also included clinical immunology services as, currently, more allergy patients requiring specialist advice are seen by immunologists, than by allergists.

The project centred on a multi-disciplinary approach to delivering allergy and immunology service improvement creating linked – but separate – paediatric and adult services, delivered from a number of locations across the region. Taking into account the population distribution of the North West, the overall vision of the project was to build on existing specialist-led services which would act as ‘hubs’ in Liverpool, Manchester and Preston and which, together, now form a networked inter-city allergy centre (the North West Allergy and Clinical Immunology Network). This includes not only specialist allergists and immunologists, and clinicians in other specialties with particular expertise in allergies, but also specially trained nurses who work out in the community, taking their specialist knowledge and skills into primary care settings. GPs with a Special Interest (GPwSIs) and general paediatricians with a special interest in allergy are also linked to the networked centre.

A number of multi-disciplinary working groups were established as part of the project. They each identified a clinical lead as Chair and were tasked with developing sustainable service improvements in the following five areas: specialised adult allergy services; specialised adult clinical immunology services; specialised paediatric allergy and clinical immunology services; specialised immunology laboratory services; regional allergy and immunology nursing.

During 2008 and 2009, and largely in support of the project, the NWSCG committed an additional £1.8 million to allergy and clinical immunology services as non-recurrent ‘pump prime’ funding to kick-start service improvements. These included the employment of additional specialists to expand capacity and the provision of increased support to a number of general paediatricians who were already running dedicated allergy clinics within district general hospitals. This injection of pump-prime funding has allowed time for services to stabilise and become more sustainable.

Working with related specialties is important in the diagnosis and treatment of patients at the more severe and/or complex end of the allergy spectrum. To improve appropriate referral and management of these patients between primary, secondary and tertiary care, related specialties joined forces to develop a set of ‘ideal generic patient pathways’.



As a result of the project, initial service specifications for allergy and immunology have also been agreed (Appendix A).

Through the North West Faculty of the Royal College of General Practitioners (RCGP), GPs in the region were involved in the development of a training programme which resulted in three primary care study days. The demand for places and the positive feedback from the events suggests an enthusiasm and a willingness on the part of a significant number of GPs to improve the care they offer to allergy patients (Appendix B).

There has been a regional approach to patient involvement and education with a patient-focused 'Shaping the Future of North West Allergy Services' workshop (Appendix C) and involvement in the Manchester Science Festival.

The project has led to improved commissioner understanding of issues relating to allergy and immunology needs and service provision.

The importance of developing a tariff structure that reflects the different levels of complexity of work in allergy has been emphasised through the development of the Network. Efforts to provide further useful advice to the national process for achieving this are continuing (Appendix D).

## **Conclusion**

Completion of this project will require the emerging SHA Clusters and the NHS Commissioning Board to consider how the lessons learnt in its first phase might be appropriately applied in the different parts of England. Clinical Commissioning Groups (CCGs) may use this learning to better inform service delivery and commissioning intentions within both primary and secondary care, to ensure that every NHS pound spent delivers quality care in the right place, at the right time. The lessons may also be of interest to the governments in Wales, Scotland, Northern Ireland, the Channel Islands and the Isle of Man.



# Introduction

## National context

There has been a dramatic increase in the prevalence of allergies in the developing world over recent decades, making allergy the most common disease of our time.

More than one third of the general population has an allergy of some kind and, once established, many of these allergies tend to be life-long, despite treatment. The incidence of the most serious, life-threatening type of allergic reaction – anaphylaxis – also continues to rise.

The presence of an allergy in the family can have an enormous effect on a person's life, and on the lives of spouses, parents, siblings and the wider circle of relatives and friends, as well as on those they come into contact with outside the home. Even the most seemingly innocuous of allergies such as hayfever can impact on a person's quality of life, affecting their work or school performance, whilst food allergies can turn activities such as shopping or eating out into events filled with anxiety.

Despite the devastating effect allergies can have on people's lives there remains a shortage of capacity and capability to diagnose, treat and manage this vast range of conditions in the NHS.

Concern about this lack of provision has been voiced at a national level on several occasions over the past few years.

In 2003 the Royal College of Physicians published 'Allergy: the unmet need – A blueprint for better patient care', reporting on the 'dangers to patients caused by serious deficits in NHS allergy care services at a time when allergy is on the increase'<sup>1</sup>.

This was followed in 2004 by the House of Commons Health Committee's sixth report which looked at the quality of NHS allergy service provision and found that 'serious problems existed' in the care of allergy patients<sup>2</sup>. The Committee recommended that allergy training be added to the curriculum for trainee doctors and that specialist allergy clinics should be developed across the country. It reported that those working in primary care lacked 'the training, experience and incentives to deliver services'.

In 2006 the Department of Health published its 'A review of services for allergy'<sup>3</sup>. This report analysed the need for allergy services and assessed whether that need was being met. It concluded that as many as 10 million people were expected to self-manage their allergy or be treated symptomatically in primary care. This review found that the NHS needed 'substantially more capacity in services for allergy generally, including clinical specialists'. Further epidemiological information relating to allergy can be found at Appendix E.

The House of Lords Science and Technology Committee inquiry into allergy in 2007<sup>4</sup>, chaired by Baroness Illora Finlay of Llandaff, recommended a number of practical steps including the development of expert centres which would lead service improvements.

The Committee recommended that one of these centres, headed by a full-time allergy specialist, should be established in every strategic health authority area. These centres would act as 'clusters of expertise' and should include consultants with an interest in allergy from various specialties.

This report was followed in 2010 by a Royal College of Physicians publication 'Allergy services: still not meeting the unmet need'<sup>5</sup>, again chaired by Baroness Finlay, which provided an update on progress made in the development of England's allergy service provision following the 2007 House of Lords report.

Whilst this update did not accurately reflect progress made in the North West in addressing some of the original recommendations, due to the timing of its publication, it did highlight the general failure to improve services from their 'Cinderella' status.

<sup>1</sup> *Allergy: the unmet need – A blueprint for better patient care* – Royal College of Physicians Working Party on the provision of allergy services in the UK. Royal College of Physicians, June 2003.

<sup>2</sup> House of Commons Health Committee, sixth report of the session 2003-4, October 2004.

<sup>3</sup> *A review of services for allergy: the epidemiology, demand for and provision of treatment and effectiveness of clinical interventions*; Department of Health, July 2006.

<sup>4</sup> House of Lords Science and Technology Committee report on allergy, sixth report of the session 2006-7, September 2007.

<sup>5</sup> *Allergy services: still not meeting the unmet need*, report of the Joint Royal College of Physicians and Royal College of Pathologists Working Party, June 2010.



<sup>6</sup> *Allergy: the unmet need. A blueprint for better patient care* – Royal College of Physicians Working Party on the provision of allergy services in the UK. Royal College of Physicians, June 2003.

<sup>7</sup> *A framework for an adult allergy network in the North West: the North West integrated clinical allergy service*, 2003. [http://www.nwscg.nhs.uk/docs/Reports/Allergy/North\\_West\\_Adult\\_Allergy\\_Network\\_Framework\\_Report.pdf](http://www.nwscg.nhs.uk/docs/Reports/Allergy/North_West_Adult_Allergy_Network_Framework_Report.pdf)

<sup>8</sup> Government response to the House of Lords Science and Technology Committee report on allergy (6th report of the session 2006-7).

## North West context

Prior to the publication of the Royal College of Physicians' report in 2003<sup>6</sup>, concerns had been raised in the North West of England about the lack of a full-time allergy specialist in the region and the isolation of the few clinicians working in this field. A small clinical working group, chaired by Roy Dudley-Southern, now Associate Director (Strategy) of the NWSCG, was established in 2001 to develop a strategy for allergy services.

This work resulted in a document in early 2003 - 'A framework for an adult allergy network in the North West: the North West integrated clinical allergy service'<sup>7</sup> – which was agreed 'in principle' by North West primary care trusts and stimulated discussion nationally, although it was not implemented in the North West. Further work carried out in 2006 by Dr Mansel Heaney and Dr Matthew Helbert, and sponsored by Mike Burrows, then Chief Executive of NHS Salford, in respect of clinical immunology services also provided additional background to the current project and gave extra emphasis to the issues that needed to be addressed.

In its response<sup>8</sup> to the 2007 House of Lords report the Government made particular mention of the recommendations relating to the setting up of an allergy centre in each SHA. One of the recommended actions called for the establishment of a lead SHA which could work with its primary care trusts in developing such a centre.

The Government concluded that any future development and provision of services for allergy would require a much clearer understanding of the skills and competencies needed within a workforce to ensure high quality cost-effective care at all stages of the patient's journey.

The response made clear that the Government would explore the feasibility of establishing a lead SHA for allergy as 'a mechanism for increasing co-ordination and co-operation' and would liaise with interested parties, including SHAs and Specialised Commissioning Groups (SCGs). The Department of Health wrote to all SHA Chief Executives seeking expressions of interest and the North West SHA was appointed in August 2008.

The pilot received non-recurrent funding from the Department of Health for a dedicated project manager, and to commission research by the University of Liverpool's Clinical Evaluation Unit (Appendix F). There was no funding from the Department for service enhancements.

This report sets out a brief history of the project, identifies the lessons learnt and makes recommendations for the future.

The authors are clear that while many opportunities exist to improve allergy services, there are just as many potential barriers to progress which the NHS Commissioning Board and Clinical Commissioning Groups must address together if patients with allergy are to see any real improvements in the future delivery of their care.

It is hoped that the lessons learnt during the project's lifetime will contribute to the knowledge base upon which future local, regional and national planning decisions for allergy and immunology services can be taken.



# Development of the North West project

Part of the context for the project was that although specialised allergy services are included in the Specialised Services National Definition Set (SSNDS), allergy activity is not procured by the NWSCG. Procurement is through local PCTs, however the strategic assessment of health needs and the planning of tertiary service provision are led by the SCG.

The pilot project was taken forward by the NWSCG acting on behalf of the North West SHA and the 24 primary care trusts in the region.

Taking into account the population distribution of the North West, with major conurbations centred on Liverpool and Manchester, and a group of smaller towns near to Preston, plus the shortage of staff with necessary skills, it was decided that improvements should build on existing specialist-led services and form a networked inter-city allergy centre with arms in those areas. Each arm would act as a 'hub' for the primary and secondary care services in its area.

Working with key stakeholders, including patient groups and clinicians, the NWSCG and its specialised commissioning team led the implementation of a service development plan that centred on the delivery of network-based, integrated allergy services for children and adults across the region.

From the outset the North West work also included the area of clinical immunology as, overall, there were similar issues of capacity and sustainability in that service and, currently, more allergy patients are seen by immunologists than allergists. Work also focused on the region's specialist laboratory immunology diagnostic services which provide essential tests to meet the needs of a wide range of major medical specialties including general medicine, paediatrics, renal medicine, rheumatology and those treating HIV/AIDS and leukaemia, in addition to tests for allergic disease and primary immunodeficiency.

The large-scale transformational programme which has been introduced for the NHS, known as QIPP (Quality, Innovation, Productivity and Prevention) provided a context for the review of current services and the consideration of developments, as did the aspiration to provide 'care closer to home' where this can be achieved efficiently and effectively.

The lead manager for allergy and immunology for the NWSCG was Simon Banks, starting work on a Cheshire and Merseyside footprint, initially, in 2005, before widening his remit following the establishment of the current NWSCG in 2007. When he left, the lead role for the NWSCG was picked up by Roy Dudley-Southern.

Louise Sinnott was appointed as full-time Project Manager in February 2009 and continued in that role until her secondment ended in January 2011. Her role was to work across all organisations involved in commissioning and providing adult and paediatric allergy and clinical immunology services to support the development and implementation of service improvement plans.

Louise has continued to offer advice since leaving this role and has co-authored this report.



<sup>9</sup> 'A framework for an adult allergy network in the North West: the North West integrated clinical allergy service', 2003. [http://www.nwscg.nhs.uk/docs/Reports/Allergy/North\\_West\\_Adult\\_Allergy\\_Network\\_Framework\\_Report.pdf](http://www.nwscg.nhs.uk/docs/Reports/Allergy/North_West_Adult_Allergy_Network_Framework_Report.pdf)

## A multi-disciplinary approach to allergy service delivery

It was established at the initial scoping stage of the project that:

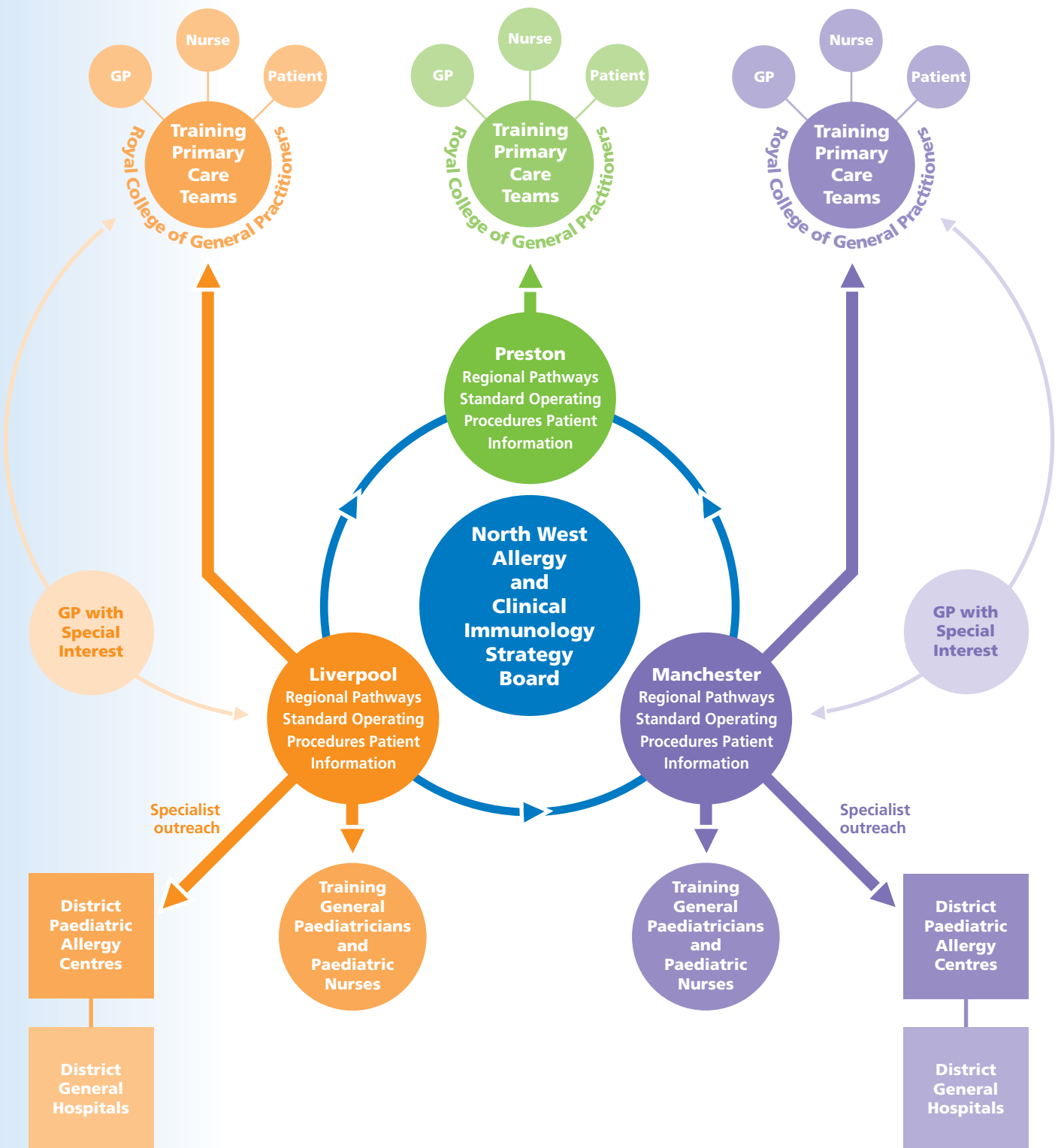
- As identified in the 'North West Framework' document<sup>9</sup> referred to on page 7 the huge unmet need for service capacity in allergy and immunology, and the population's distribution, could not be addressed by a single site allergy centre in the North West of England, thereby necessitating some sort of network arrangement. Similarly the training needs of primary and secondary healthcare professionals would be best met via a 'networked' approach.
- It was essential to support improvements in the diagnosis and management of allergy in both primary and secondary care in order to ensure that the vast majority of patients could be treated nearer to their homes, and to reduce pressure on tertiary centres so that they could concentrate on those patients who most needed their skills.
- Given that allergy affects the lives of millions of people every year (and, for a few, is potentially life-threatening), and that primary immunodeficiency represents a group of rare, life-threatening diseases, service development for allergy and clinical immunology must be considered separately in order to develop appropriate models of care. This is more complicated than it might initially appear as a significant element of the work of immunologists currently is the treatment of allergy patients.
- It should be noted that general paediatricians in many local district general hospitals provide paediatric allergy services, which means that only the most severe and/or complex cases are referred to a tertiary centre. The 'general adult physician' in local hospitals has largely disappeared. Therefore, without a similar structure in adult secondary care, a broader spectrum of adult patients is referred for specialist allergy opinion or care. The exception to this is allergies linked to established specialties such as respiratory medicine, dermatology, gastroenterology or ENT in which there may be individuals with particular expertise in allergies related to their main specialty.

The patterns of specialised allergy and clinical immunology service provision in the region, looking at historical and prospective activity trends (as far as this was possible), access, capacity, capability, payment mechanisms and performance, were reviewed. There was also an exploration of how specialist allergy services might successfully engage with assessment, treatment and support services in primary care, and local district general hospitals.

This project centred on a multi-disciplinary approach to achieving allergy and immunology service improvement creating linked – but separate – paediatric and adult services, delivered from a number of locations across the region.



## Development of allergy services for children and adults in North West England



**Table 1: North West NHS: Specialised allergy and immunology service providers:**

Trust	Service provided
Alder Hey Children's Hospital NHS Foundation Trust	paediatric allergy and immunology
Central Manchester University Hospitals NHS Foundation Trust	adult immunology (with allergy) paediatric allergy and immunology
Lancashire Teaching Hospitals NHS Foundation Trust	adult immunology (with allergy)
Royal Liverpool and Broadgreen University Hospitals NHS Trust	adult allergy and immunology
Salford Royal NHS Foundation Trust	adult immunology (with allergy)
University Hospital of South Manchester NHS Foundation Trust	adult allergy

**Note.** Most of the consultants with specialist allergy expertise in dermatology, ear, nose and throat surgery, gastroenterology and respiratory medicine, work in one or more of the hospital trusts listed above.

The bringing together of tertiary allergy providers to form an inter-city allergy networked centre, and improving their links with services in primary and secondary care was – and continues to be – co-ordinated via the North West Allergy and Clinical Immunology Network Strategy Board. For membership of the Board, see Appendix G.

The Network Strategy Board oversees and directs the work of a number of implementation groups and provides a strategic focus for tertiary allergy and clinical immunology services across the North West. The Board is made up of lead specialist consultants and laboratory staff, patient and carer representatives, specialist nurses, service managers and commissioners.

Five multi-disciplinary working groups were established. They each identified a clinical lead as Chair and were tasked with developing sustainable service improvements in the North West in the following areas:

- Specialised adult allergy services
- Specialised adult clinical immunology services
- Specialised paediatric allergy and clinical immunology services
- Specialised immunology laboratory services
- Regional allergy and immunology nursing

The project manager attended all bi-monthly working group meetings to ensure consistency and a broadly common approach to enable the network to share best practice and to identify common problems and associated risks affecting project delivery.



## North West Allergy and Clinical Immunology Strategy Board



The working groups developed generic allergy care pathways for children and for adults (see Appendix H). Disease-specific pathways for children were developed by the Royal College of Paediatrics and Child Health<sup>10</sup> with the active involvement of North West Allergy Network members at all levels of that project.

Initial service specifications for tertiary adult and paediatric allergy services were developed jointly between the specialised commissioners and the specialist allergy service providers for inclusion in the 2011/12 contracts (see Appendix A). It is recognised that these need further refinement.

The Network organised a number of events during the life-time of the project including a conference held at the 'half-way stage' which was attended by Baroness Finlay. Network members updated delegates on progress being made in both adult and paediatric services, including some key staffing appointments and the development of a number of district paediatric allergy centres run by general paediatricians with an interest in allergy, with regular support from a visiting tertiary specialist.

<sup>10</sup> Royal College of Paediatrics and Child Health, 'Care pathways for children with allergies', <http://www.rcpch.ac.uk/child-health/research-projects/care-pathways-children-allergies/care-pathways-children-allergies>



Patient representatives attended the conference and also took part in an engagement event for patients and their carers in Warrington in 2010. Appendix C provides a full report of this event.

The Network organised a series of study days through the North West Faculty of the Royal College of General Practitioners. Held during September and October 2010 at venues in Liverpool, Manchester and Blackpool, they were attended by more than 100 primary care staff. See Appendix B for a full evaluation report relating to this event.

Members also took part in the Manchester Science Festival, raising awareness of allergic conditions and inviting volunteers to take part in allergy testing.

Finally, recognising the issue of service sustainability and the major part played by finance in that, the Network Board initiated a project to compare the costs of providing the tertiary services in the North West and give guidance on appropriate tariffs. The details of this can be found at Appendix D. It should be noted that this work is continuing.

# Allergy: The Lessons

During the course of the project a large number of lessons have emerged. Some of these lead directly to recommendations for future action by different NHS organisations. Others may be of local or wider interest but do not, in themselves, suggest particular actions.

We have attempted to group together lessons which we believe are linked, regardless of whether or not they have recommendations attached.

## Lesson 1

There is a need for improved education of commissioners about the impact of allergies on individuals and of the time and treatment implications of this for primary care. For those with more complex or rare allergies it appears to be largely a matter of chance as to which pathway they follow with the fortunate ones going fairly directly to specialised services but others being referred from specialty to specialty, often undergoing unnecessary, sometimes invasive, investigations and even operations.

## Lesson 2

Patient stories provide a powerful case for change and are useful training tools for clinical teams outside tertiary centres. Patients need a holistic approach to their care, characterised by good communication between clinicians in different specialties or working in different settings. They also need improved education supported by reliable information at the point of diagnosis, leading to optimal self-management.

## Lesson 3

A 'one size fits all' approach to allergy service provision is not realistic, practicable or achievable.

A single allergy centre for the North West was found to be an unworkable model mainly because of the size and geography of the region – a population of more than 7 million distributed across two significant urban areas as well as large towns on the edge of rural areas and an out-of-area referral population from North Wales. In order to ensure that patients were cared for as close to their homes as possible, a network model, integrating existing services, was considered the most sensible option for this particular region.

## Recommendations

Where there is no single population focus with good transport links from most parts of a given area, a network would be the most appropriate model for the future development of allergy services.

For this to function effectively it would need:

- Support, in terms of paid sessions for clinical leads to have 'protected' time to commit to the network and to education and training.
- Network hosting/ownership by a Clinical Commissioning Group or specialised commissioning arrangement, rather than by an individual hospital trust.
- Dedicated, network management support to administer meetings, at the very minimum, but optimally to develop training, support improved commissioning of services, including governance, and address business support issues.



#### **Lesson 4**

Linking clinicians with an interest in allergy provides an opportunity to drive up standards and increase awareness of patient pathways. Examples include facilitating the development of standard operating procedures for both adults and children and of district paediatric allergy 'centres' to become centres of excellence for the care of children with allergies for a wider area.

#### **Lesson 5**

Unless there are good reasons for major changes, developments in allergy services should focus on supporting **existing** service provision to ensure the retention of scarce clinical expertise.

#### **Recommendation**

Specialised allergy services should be developed on a regional footprint, in a partnership between tertiary providers. This will ensure the sustainability of the specialist services and facilitate their governance.

#### **Lesson 6**

There is a national shortage of allergists. The few allergy trainees for whom 'training numbers' have been agreed are often 'snapped up' by the trusts within which they complete their training. As a result recruitment to additional posts in the North West, funded by the primary care trusts through the specialised commissioning arrangements, was slow. In some instances, the provider trusts had to look outside the UK in order to attract suitably qualified allergy specialists. It has become clear that it would be difficult to 'grow our own' specialists, even if additional training numbers became available, because academic and service allergists, at the behest of their trusts, are too busy seeing patients to train juniors. This is a situation which is encouraged by purely activity-based tariff arrangements.

#### **Recommendation**

Additional allergy training numbers should be allocated and more services enabled to operate as training centres with appropriate tariff adjustments to recognise the additional costs those centres will incur.

#### **Lesson 7**

The shortage of allergy trainees in England means that the immunologists who are currently providing specialised allergy services will need to continue to do so for the foreseeable future. As a greater proportion of appropriate patients are enabled to be seen by specialist allergists, this element of immunology work will diminish. The longer term impact on immunology services of this development will need to be considered.



### **Lesson 8**

Patients with complex needs, for instance those in whom their allergy affects more than one body system, are likely to remain in tertiary care but the vast majority of allergy patients could be managed at earlier stages in the pathway given improved diagnostic and treatment capabilities in primary and secondary care teams.

### **Lesson 9**

Many referrals to tertiary allergy services are avoidable in that the issues should have been managed earlier in the patient pathway. Some of these patients can be identified from the referral letter and the requested advice given without the patient attending the tertiary service. However, the remainder have to be seen to enable the referral information to be clarified/expanded. In both instances the tertiary clinicians have to act as secondary care clinicians, reducing the time available for them to use their scarce skills for the benefit of patients with complex or severe allergic diseases.

### **Lesson 10**

Many primary care clinicians appear to lack confidence in diagnosing and treating allergies. They will prescribe drugs to alleviate the symptoms of the most common allergies but do not feel confident with the less common conditions or those that do not respond to standard treatments. Some are unaware of specialist allergy services including those provided by consultants with a special interest in allergies whose main specialty is dermatology, ear nose and throat surgery, gastroenterology or respiratory medicine.

### **Lesson 11**

New ways of working need to be established to encourage and support improvements in care given outside the specialist centres, i.e. in primary and secondary care. However, the challenge is finding clinicians with a) a particular interest in allergy and b) their practice or trust willingly accepting that, at the sessions supported by a more specialist, visiting allergist, fewer patients may be seen.

#### **Recommendations relating to lessons 8-11**

Service improvements should centre on:

- Related specialties working jointly on the production of service specifications covering all parts of the care pathway developed collaboratively between commissioners and service providers;
- Outreach by specialists to support and develop clinicians with an interest working more locally;
- Outreach by specialist nurses to support primary care teams;
- Support for the introduction of general practitioners with a special interest and training in allergy;
- A much greater emphasis on education and training at all levels of provision and for all the professions involved.





## Lesson 12

Current information systems do not support the recording of accurate activity data for allergy patients and services. This means that it is very difficult to convince primary and secondary care commissioners of the need for service development outside tertiary centres without evidence of the numbers of patients being seen in those settings. This may even be the case when, for instance, a dermatologist has regular clinic sessions dedicated to allergy patients.

### Recommendation

Improved diagnostic and treatment codes for allergic disease and their systematic use in all specialties regularly seeing allergy patients would provide evidence to inform service development decisions. This applies particularly to activity undertaken in the outpatient setting.

## Lesson 13

It has become clear that in general there is a greater understanding of allergies, both in diagnostic and treatment terms, amongst secondary care paediatricians than among their counterparts in adult medicine. Therefore, the models of care for adults and children may need to reflect this variation.

### Recommendation

Improved training and education of those secondary care clinicians who are most likely to encounter allergies would lead to the more rapid identification of the nature of presenting problems and enable them to be managed appropriately.

For children who require on-going care, clear transition plans must be in place to ensure the smooth, supportive continuation in that care as they move to adulthood. These plans must be based on a sympathetic understanding of the major life changes that individuals face as adolescents and young adults.

## Lesson 14

Single-handed practice in allergy leaves services vulnerable, particularly if they are not generating sufficient income for their trusts to cover their costs.

### Recommendation

Pump priming investments, linked with the development of a care network, are essential to allow new, fledgling services or small established services to become sustainable without the added pressure of the need to generate sufficient income to cover their costs immediately.



### Lesson 15

A 'bottom up' costing exercise has revealed considerable variations in clinical practice and resources between allergy service providers. In some instances there are inadequate local tariffs which offer little incentive for trusts to develop services. Until that situation is rectified by a sufficient mandatory national tariff, preferably with flexibility to accommodate some variations in clinical practice, significant differences between services is likely to remain.

#### Recommendation

Tariffs need to be introduced which adequately cover the costs of the services, are sufficiently flexible to allow for differences in clinical practice and include provision for the important training and education role of the clinical specialists which does not involve patient contacts or requires fewer patients to be seen in a session.

### Lesson 16

The importance of a competently delivered, adequately resourced, integrated patient pathway, able to respond appropriately to all levels and complexities of patient need, has been demonstrated through this project. Unfortunately, a pathway with these characteristics does not exist in many parts of the country, including the North West of England. This means many patients do not receive adequate care and are left to cope with their allergies with little support.

#### Recommendation

The effective delivery of such a pathway requires the commissioners for each of the levels of care to work closely together. The relatively small tertiary element will need to be part of the specialised commissioning arrangements, if improvements in equity of access are to be attained and service sustainability assured, with the other levels of provision subject to more local commissioning arrangements. Like many other services with a tertiary dimension, developing an integrated patient pathway requires the different commissioners to work closely together. This will not be simple to accomplish.

### Lesson 17

Given the emerging arrangements for the commissioning of primary, secondary and tertiary care in England, and the financial constraints within which the NHS needs to operate, it is difficult to be confident that allergy will be an early priority for commissioners. This means that inequity of patient access to secondary and tertiary level allergy services across England, and the vulnerability of many of the specialist allergy services will remain.

#### Recommendation

Specialist allergy services should continue to be included in the National Specialised Services Definition Set and, from 2013, be actively commissioned directly by the new NHS Commissioning Board as part of an integrated patient pathway. Such a pathway is unlikely to emerge without strong leadership by the specialised service commissioners.

# Summary and conclusions

## Context

The incidence and prevalence of allergic disease in the population is increasing. Allergic disease probably affects more members of the population than any other group of diseases. It results in much misery, the failure of individuals to learn and work to their full potential and a number of possibly avoidable deaths.

Despite this there has been little commissioner involvement with or even interest in this area leaving the relatively few, often poorly staffed, tertiary allergy services extremely vulnerable. This gives added emphasis for such services, including those provided by clinicians with a special interest in allergies related to their core specialties (dermatology, respiratory medicine, gastroenterology and ENT surgery), to be specially commissioned.

Resources are wasted and people with multiple allergies and/or a single allergy with confounding co-morbidities are ill-served when they are passed around from symptom-related service to service rather than having the opportunity of a holistic approach, offered by an allergy specialist.

## Whole pathway

PCT investment, Department of Health pilot status and dedicated project management to support service improvements have together helped to improve the 'visibility' of the North West's allergy and immunology services.

Bringing together colleagues with an interest in allergy in the form of a clinical network has resulted in new ways of working including:

- Single-handed services being linked with network colleagues for cross-centre support.
- Linking with colleagues to share views and experiences in the management of complex cases.
- The formation of a North West Allergy and Immunology Specialist Nurse Group that is developing a competency framework for allergy nursing at all levels of the patient pathway.
- Opportunities to improve clinical governance including cross-regional audits.
- A regional approach to education, training and patient information.

The North West Allergy Project has increased commissioners' awareness of issues around allergy service provision throughout the patient pathway but may have been less successful in stimulating action particularly in the context of 'efficiency savings' and delivering NHS reforms.

Inadequate or absent data collection and clinical coding across primary, secondary and tertiary allergy and immunology care is an obstacle to service review, planning and development.



### **Primary care**

The project demonstrated that there is considerable clinical interest in opportunities to improve skills in the diagnosis, treatment and management of allergy in primary care.

The training and education of primary care clinicians and those in secondary care who wish to develop their skills in the area of allergy should be an integral part of the job plans of allergy specialists and should be recognised in the Payment by Results (PbR) system.

There is a lack of awareness in primary care both of existing specialist allergy services, either separate from or linked with immunology, and of clinicians in other specialties who have a sub-specialty interest and expertise in the diagnosis and treatment of allergies related to their main specialty.

Commissioners have not appreciated the burden of allergic disease in the population and appear reluctant to engage in initiatives to address deficits in primary care. Without tangible pressure on services, i.e. breaches in waiting times or voiced concerns from patients, MPs and pressure groups, commissioners are unlikely to prioritise this area.

### **Secondary care**

From the limited evidence available in the report commissioned from the University of Liverpool's Clinical Evaluation Unit (Appendix F) as part of the project, it would appear that there is a mixed picture regarding the secondary care treatment of adults with allergies, with some clinicians not being fully aware of more specialist allergy colleagues and others not recognising the need to/not referring patients to allergy specialists for the investigation of complex allergic disease. The report indicates that these individuals would rather look to colleagues in their own specialty than allergists per se. Others, however, with a keen interest in this clinical area, want to see the development of specialist allergy services within the region.

The position in secondary children's services is better with general paediatricians having more experience of dealing with children with allergies and a generally clearer understanding of when a child needs a higher level of specialist skill.

### **Tertiary care**

Whilst a single-centre model of tertiary allergy provision may be appropriate for some parts of the country (possibly where there is a single, concentrated population centre which is the focus for a large rural hinterland), it will not address the needs in areas where there are several such centres, as in the North West of England.

A significant proportion of patients referred to (and often seen) in tertiary allergy services could be managed within a primary and secondary care setting. This would be facilitated by improved opportunities for clinicians at those levels to develop their skills in the diagnosis and treatment of patients with less complex allergic disease or fewer confounding co-morbidities.



There are patients who require the skills of tertiary allergists who take a long time, often with many other referrals and procedures, before reaching them. This suggests a major training and information need in both primary and secondary care that should be included in the job plans of tertiary specialists.

Specialist allergy doctors require adequate support from specialist nurses with assessed competencies, whose skills should not be diluted by temporary transfers to fill gaps in other services.

Threats to the future stability of the North West's diagnostic immunology centres have hindered progress to standardise laboratory allergy test procedures. Any future reduction in the number of immunology services and/or their linked laboratories could affect allergy services and this must be considered before any plans are finalised.

Although there is now more joined-up working in this part of England, through the North West Allergy and Clinical Immunology Network, many allergy specialists function to a greater or lesser extent in isolation. It is most important that they are linked on a permanent, sustainable basis through some sort of network, which should aim to develop and manage a clinical governance system, including the introduction of shared standard operating procedures, guidelines and clinical audit.

Specialist allergy and immunology services are seen to be vulnerable and sometimes unsustainable. This was particularly the situation for those serving the populations of South Cumbria and most of Lancashire, due to the inadequate tariffs being used. The specific issue has been resolved but the general problem of tariffs not sufficiently reflecting the complexity of this area of practice, particularly at the tertiary end of the spectrum, remains.

It is particularly important that allergies affecting more than one body system are referred to a consultant allergist.

After a confirmed diagnosis and management plan is given at a tertiary service, it would be appropriate for the long term management of many patients to be referred back to a secondary or primary care service where the skills exist at those levels. However, patients with the most complex needs will probably need to stay within tertiary care.

There should be much improved arrangements for the transfer of care from children's to adult services at secondary and tertiary levels for those patients whose need for support covers that part of their lives. This will require services to be aware of and sensitive to the specific needs of young people in this particular age group.

In any process of developing plans to address the need and demand for tertiary allergy services, account must be taken of the significant current role of clinical immunologists and the need for the support of specialist immunology laboratories.



## Next steps

At the time this report is being written, the NHS commissioning landscape is undergoing radical change with the introduction of Clinical Commissioning Groups, Clinical Senates and the NHS Commissioning Board, as well as the interim clustering of primary care trusts and strategic health authorities (specialised commissioning groups are to be clustered on the same footprint as the SHAs).

What might this developing environment mean for services for people with allergic diseases?

The revised commissioning system is intended to give general practitioners more influence than the previous arrangements. The interest shown by GPs in allergies and in improved opportunities for training during the pilot may be reflected in the new system's future commissioning decisions.

However, it is difficult to be confident that allergy will be an early priority for the emerging arrangements for commissioning secondary and tertiary care, particularly given the financial constraints within which the NHS needs to operate, unless significant external pressure is brought to bear.

What is of considerable importance in respect of these arrangements, given the current differential access to specialist allergy services across England and their vulnerability, is that they should continue to be included in the National Specialised Services Definition Set and, from 2013, be actively commissioned directly by the new NHS Commissioning Board.

A number of tariff issues have emerged during the pilot. Firstly, the consequences of specialist service tariff inadequacies have been highlighted with the complication of variations in practice making this difficult to address. Secondly, the pilot has demonstrated the need for allergy specialists to devote some of their time to training and mentoring practitioners in primary and secondary care. However, tariffs reward services for 'seeing' patients and not for other activities. Indeed, in this respect they actually produce a contradictory pressure in that empowering clinicians earlier in the patient pathway is likely to reduce the number of patients referred for specialist care.

To complete and build on the work initiated by the pilot project, the intention is that this report will be taken forward by the Northern SHA cluster and the emerging NHS Commissioning Board for wider discussion across England. The lessons are relevant to a wide range of statutory and non-statutory organisations, many of which can play a part in addressing them or ensuring that they are addressed.

It is hoped that this report will also be of general interest and particularly useful in those areas where services for patients with allergic diseases are inadequate and need to be developed.



# Appendices

**Appendix A:** Initial service specifications for tertiary adult and paediatric allergy services

**Appendix B:** A collaborative approach to training and education

**Appendix C:** Patient engagement event evaluation report

**Appendix D:** Developing an allergy tariff structure

**Appendix E:** Epidemiology

**Appendix F:** Report on the Progress of a Project to Assess Adult Allergy Care in District General Hospitals in North West England – Aintree Health Outcomes Partnership @ University of Liverpool

**Appendix G:** Membership of the North West Allergy and Clinical Immunology Network Strategy Board

**Appendix H:** Generic allergy care pathways



# Appendix A: Initial service specifications for tertiary adult and paediatric allergy services

In order to support service improvement, some initial work on service specifications was undertaken, in partnership between specialised commissioners and specialist allergy service provider organisations for inclusion in the standard NHS contracts for 2011/2012.

The service specifications are based on agreed evidence-based care and treatment models which describe a specialised allergy service model; the conditions seen; exclusion criteria; interdependencies with other services within the NHS, and appropriate care pathways.

They support the provision of a high quality, accessible and sustainable service that meets the needs of the local population, and reflects the effective use of resources within the North West. There is a particular emphasis on appropriate support from other clinical specialties, mainly ENT, dermatology, gastroenterology, respiratory medicine and paediatric medicine and a focus on the integration of specialist care with primary, secondary and other specialty-related care providers where appropriate, stressing the importance of the education of, and communication with, primary and secondary care teams.

<b>Service</b>	Specialised Allergy Service: Adult (National Definition set 17) <a href="http://www.specialisedcommissioning.nhs.uk/index.php/key-documents/specialised-services-national-definitions-set/">http://www.specialisedcommissioning.nhs.uk/index.php/key-documents/specialised-services-national-definitions-set/</a>
<b>Commissioner Lead</b>	North West Specialised Commissioning Group
<b>Provider Lead</b>	Central Manchester University Hospitals NHS FT Lancashire Teaching Hospitals NHS FT Royal Liverpool and Broadgreen University Hospitals Trust Salford Royal NHS FT University Hospital of South Manchester NHS FT
<b>Period</b>	2010/11

## 1. Purpose

### 1.1 Aims

- Describe specialised allergy service provision.
- Support a service model that provides a high quality, accessible and sustainable service that meets the needs of the local population and reflects effective resource use within the North West.
- Integrate specialised/tertiary care with primary, secondary and other specialty-related care providers.





<sup>11</sup> Gupta R, Sheikh A, Strachan DP, Anderson R. *Increasing hospital admissions for systemic allergic disorders in England: analysis of national admissions data*; BMJ 2003; 327: 1142-43

## 1.2 Evidence base

Specialised allergy services (National Specialised Service Definition Set 17) incorporate the diagnosis and treatment of allergic conditions in the specialties of allergy and clinical immunology, though other specialties may also be involved.

Allergic disease is common and prevalence has increased 2-3 fold in the last 20 years.

There have been significant increases in admissions for systemic allergic diseases (anaphylaxis, angioedema, food allergy, and urticaria) in England between 1990-1 and 2000-1 which almost certainly reflect an increase in incidence<sup>11</sup>.

The bulk of allergic disease is treated by GPs in primary care. At the local hospital level allergy is treated in a number of different specialties including by respiratory physicians, ENT surgeons, dermatologists, ophthalmologists, haematologists and occupational health physicians.

Specialised allergy services provide diagnosis and care for patients with the more severe and complex problems or in other situations where an allergic aetiology is suspected. Specialised allergy services are provided mainly by allergists and clinical immunologists.

## 1.3 General overview

Immune over-reactivity or hypersensitivity to **foreign** substances (allergens), usually proteins such as foods, pollens, pet dander, insect venom or medication, is termed **ALLERGY**. Allergic conditions can be classified as either **acute**, where reactions classically appear within minutes and settle within hours to a few days, or **chronic**, where symptoms come on more gradually and last for months to years.

**Acute reactions** are usually mediated by allergen cross-linking IgE antibodies on the surface of mast cells leading to the release of inflammatory mediators such as histamine. Standard allergy tests (allergen-specific blood and skin prick tests) may be useful in supporting diagnosis. Avoidance of the specific trigger and the use of antihistamines for minor reactions are the mainstays of therapy. For acute severe allergy, intramuscular adrenaline is currently recommended.

Deaths from acute allergy are rare but many allergic disorders are chronic and they may be debilitating, involving long periods off work or school (e.g. asthma, urticaria and angioedema). Hence a long-term patient-centred model of care may be most appropriate. This will need to include appropriate arrangements for children making the transition into adult services. Allergies also cause considerable anxiety and concern in the community leading to an increasing burden of patients seeking advice from the health service. Thus key to the management of allergic conditions is the imparting of accurate and up-to-date medical information, both at an individual patient and community level.

## 1.4 Objectives

Up to 33% of adults are atopic (have an allergic hypersensitivity affecting parts of the body not in direct contact with the allergen). Only a small proportion of these patients can directly be cared for by tertiary allergy services.

The management of all, or the majority of people with allergy, at tertiary centres is a practical and economic impossibility.



The North West Allergy and Immunology Network has produced a series of ideal pathways for common allergic conditions. The pathways describe service improvements at the tertiary level of an allergy service as follows:

### Tertiary allergy services

Recommendation	Who owns	Indicator
Develop rotating consultant role with a clinical and managerial responsibility for the entire network. Tenure of post to be 3-4 years	NWSCG	Agree JD for role Agree how appointment made Administration support identified
Develop the network of specialist allergy services, supporting clinical governance (joint guidelines and audit) and improved communication	Rotating clinical lead with admin support	Administration support identified Network constitution & ToR Clinical protocols established Audit carried out
Develop regional allergy pathways	Rotating lead with individual clinicians	Agree pathways in detail Map pathways and identify obstacles
Identify resources for dietetic services for allergy across the region	Rotating lead	Discover evidence and experience base Describe service require Develop JD
Build capacity of tertiary service # 1 Double Blind Placebo Controlled Food Challenge (DBPCFC)	Clinician with interest and dietician	Agree on single location Local assessment Provide service for network
Build capacity of Anaesthetic allergy	Clinician with interest and anaesthetist	Agree on single/two location Local assessment Provide service(s) for network
Meetings for clinical governance and for individual MDTs	Rotating lead/ individual trusts	Trusts identify PAs in Job Plans Administration support identified
Increase medical and nursing staffing to enable training of and liaison with primary care	Individual allergy clinics	Identify local needs in detail Liaise with GP representatives Agree specific goals for training Agree how to continue funding of training
Provide supervision and support for Tier 2 nurses and GPwSI	Rotating lead/team at CMMC and RLBG	Posts filled Agreed PDPs/KSFs



## 1.5 Expected outcomes

The proposed service and clinical model for providing the specialised allergy service will ensure that it is integrated with primary, secondary and other providers within a networked arrangement.

Expected outcomes include:

- The development of regional guidelines, protocols, pathways and standard operating procedures for specialist allergy services (including agreed entry criteria)
- A regional approach to clinical audit
- A defined approach to education and training in primary and secondary care
- Patients being treated appropriately at lower levels within the healthcare system with the specialised services only seeing patients whose diagnoses are unclear and/or problems are complex

<b>Service</b>	Specialised Paediatric Allergy Service (National Definition set 17) <a href="http://www.specialisedcommissioning.nhs.uk/index.php/key-documents/specialised-services-national-definitions-set/">http://www.specialisedcommissioning.nhs.uk/index.php/key-documents/specialised-services-national-definitions-set/</a>
<b>Commissioner Lead</b>	North West Specialised Commissioning Group
<b>Provider Lead</b>	Central Manchester University Hospitals NHS FT Alder Hey Children's Hospitals NHS FT
<b>Period</b>	2010/11

## 1. Purpose

### 1.6 Aims

- Describe specialised paediatric allergy service provision
- Ensure a service model that provides a high quality, accessible and sustainable service that meets the needs of the local population and reflects effective resource use within the North West region
- Integrate care with primary, secondary and other care providers

### 1.7 Evidence base

Specialised allergy services (National Specialised Service Definition Set 17) incorporate diagnosis and treatment of allergic conditions from the specialties of allergy and clinical immunology, though other specialties may also be involved.

Allergic disease is common and prevalence has increased 2-3 fold in the last 20 years.

There have been significant increases in admissions for systemic allergic diseases (anaphylaxis, angioedema, food allergy, and urticaria) in England between 1990-1 and 2000-1 which almost certainly reflect an increase in incidence<sup>12</sup>.



<sup>12</sup> Gupta R, Sheikh A, Strachan DP, Anderson R. 'Increasing hospital admissions for systemic allergic disorders in England: analysis of national admissions data', *BMJ* 2003; 327: 1142-43

The bulk of allergic disease is treated by GPs in primary care. At the local hospital level allergy is treated by a number of different specialties including respiratory physicians, ENT surgeons, dermatologists, ophthalmologists, haematologists, occupational health services and in the case of children, paediatricians.

Specialised allergy services provide diagnosis and care for the more severe and complex cases or where allergic aetiology is suspected. Specialised allergy services are provided in the main by allergists and clinical immunologists.

### 1.8 General overview

Immune overactivity or hypersensitivity to **foreign** substances (allergens), usually proteins such as foods, pollens, pet dander, insect venom or medication is termed **ALLERGY**. Allergic conditions can be classified as either **acute** where reactions classically appear within minutes and settle within hours to a few days, or **chronic** where symptoms come on more gradually and last for months to years.

**Acute reactions** are usually mediated by allergen cross-linking IgE antibodies on the surface of mast cells leading to the release of inflammatory mediators such as histamine. Standard allergy tests (allergen-specific blood and skin prick tests) may be useful in supporting the diagnosis. Avoidance of the specific trigger and antihistamines for minor reactions are the main stay of therapy. For acute severe allergy intramuscular adrenaline is currently recommended.

Deaths from acute allergy are rare, particularly in children. Approximately one child dies of acute allergy/anaphylaxis each year in the UK<sup>13</sup>. Thus acute allergic children are almost never life-threatening. They do however cause significant morbidity in terms of restrictions to the child's and parent's lifestyle, disruption to school and family life, including sleep<sup>14</sup>. They also cause considerable anxiety and concern in the community leading to an increasing burden of patients seeking advice from the health service. Thus key to the management of allergic conditions is the imparting of accurate and up to date medical information, both at an individual patient and community level.

### 1.9 Objectives

As allergy is very common, affecting up to 20% of children, only a small proportion can directly be cared for by Tier 3 services and that management of all or the majority of children with allergy at Tier 3 level is a practical and economic impossibility. Before determining how a Tier 3 paediatric allergy service should be configured it is critical to understand its function. These are listed below:

**1. Education** - Health care workers within Tier 3 service possess the highest level of training and therefore theoretical and practical knowledge as to the optimal management of children with allergy. It therefore falls within their remit to help ensure that Tier 1 and 2 health care workers within the region as well as their administrative organisations (e.g. RCPCH, RCGP), as well as community and media organisations (e.g. Allergy UK ([www.allergyuk.org/](http://www.allergyuk.org/)), Anaphylaxis Campaign ([www.anaphylaxis.org.uk/](http://www.anaphylaxis.org.uk/)), radio and TV stations) are provided with information and guidelines on allergies for patients and the general public with regular accurate updated verbal and/or written information as to the natural history and management of these conditions. Tertiary input into all these tiers will help to ensure that care of children with allergies is wherever possible evidence rather than opinion based, as is commonly the case at the present time.

<sup>13</sup> MacDougall et al, 2002; Pumphrey, 2004; Pumphrey & Gowland, 2007; Summers et al, 2008

<sup>14</sup> Moore et al, 2006; Baiardini et al, 2006



**2. Clinical management of complex cases** - Children with severe, complex or unusual allergies (i) that do not respond to standard treatment (which in the case of common chronic atopic diseases is currently distributed as national guidelines) and (ii) where the quality of life is significantly affected because of the allergic condition should be seen in specialist paediatric allergy centres.

### **1.10 Expected outcomes**

The proposed service and clinical model provided the specialised paediatric allergy service will be integrated with primary, secondary and other providers within a networked arrangement.

Expected outcomes include:

- Increased capacity within existing resources through the implementation of paediatric allergy service improvement plans
- The development of regional guidelines, protocols, pathways and standard operating procedures for specialist paediatric allergy services (including agreed entry criteria)
- A regional approach to clinical audit
- A defined approach to education and training in primary and secondary care



# Appendix B: A collaborative approach to training and education

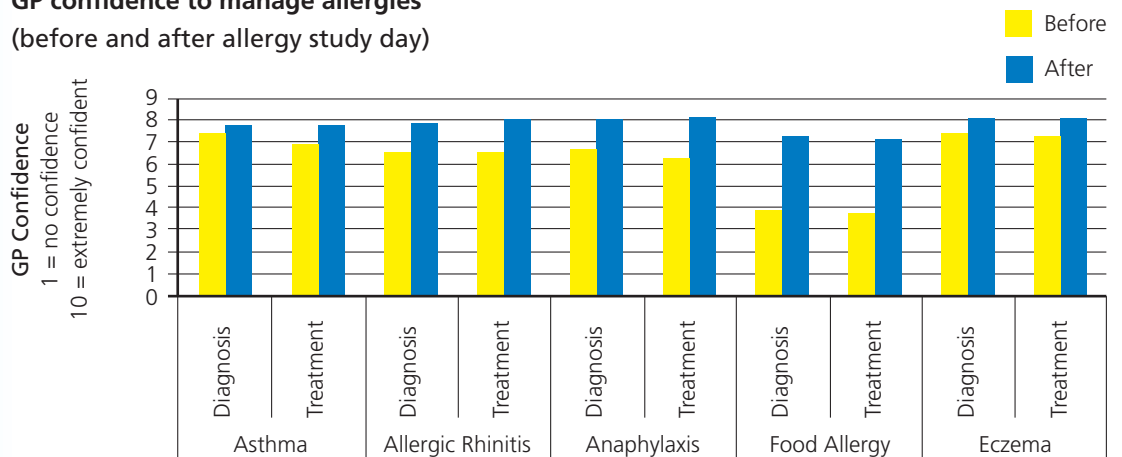
Working in partnership with the North West Faculty of the Royal College of General Practitioners (RCGP), GPs in the region were involved in the development of a training programme which resulted in three primary care study days. This involvement in the design of the training ensured that the study days were as relevant and as practical as possible in relation to patients presenting with allergic symptoms in general practice.

During September and October 2010, more than 100 GPs attended the study days at venues in Liverpool, Manchester and Blackpool.

The tailor-made programme was delivered by tertiary allergy colleagues from the North West Allergy and Clinical Immunology Network and was very well received. As a result, the RCGP North West Faculty is considering the incorporation of allergy training into its annual programme of GP education, based on the high attendance rates at the three events and the positive post-event feedback.

In 2011, the allergy nurse consultant and 'Education for Health' trainer is organising the development and delivery of an allergy course module in the North West aimed at specialist registrars (SpRs), general paediatricians, GPs, practice nurses and practising specialist allergy nurses seeking a formal qualification who would have otherwise have had to travel to London or Southampton.

**GP confidence to manage allergies**  
(before and after allergy study day)



Nine out of the 10 course participants rated the training as 'above average' or 'excellent'. Some direct quotes taken from the course evaluation forms include:

*"The day provided a useful framework for allergies commonly seen in general practice so they can be managed more effectively."*

*"Really useful information on food allergy. I will share this with partners at my practice."*

*"I found the debate about EpiPen prescribing very helpful and the need to spend more time on educating patients about their allergy. I plan to have a supply of demo pens to properly teach my patients how to use them."*

*"I am now able to make better referrals and know how to counsel patients presenting with allergies."*

*"The patient case studies were an excellent way of learning and put all the information from the day into context."*



# Appendix C: Patient engagement event evaluation report

The purpose of this report was to help support clinical teams in future patient and public engagement initiatives. All those attending the engagement event received a copy of this report.

## **Listening to Patients: 'Shaping the Future of North West Allergy Services'**

### **Executive summary**

Allergies are common and on the rise, but there are not enough NHS allergy specialists in the North West to see everyone who needs help. This report provides a summary of feedback from participants at a listening event called 'Shaping the Future of North West Allergy Services', held in Warrington in 2010. NHS allergy experts and managers working on allergy service improvements in the region invited patients, their carers and families to a meeting in order to hear their views about local allergy services.

Key themes from discussions with patients at the event:

- The majority of patients and parents will initially seek advice and treatment from their GP; patients have mixed experiences of allergy diagnosis, treatment and management in primary care and are keen to see local improvements at this level of the NHS.
- Improved communication is required between doctors in different specialties dealing with components of allergic disease.
- Patients need education for themselves, their friends, families and teachers based on reliable facts and supported by sources of information to help them manage their allergies better.
- NHS allergy testing should be signposted where appropriate. It is also important that patients are given information relating to their allergy at point of diagnosis – an accurate diagnosis is key to improved quality of life.
- Allergy patients should have planned allergy reviews as standard.



### 1.0 Background

The vision of the North West Allergy and Clinical Immunology Network is to develop specialist-led integrated allergy services for children, young people and adults in the North West. It is hoped that local changes will inform the establishment of allergy service development in other UK regions as requested by the Department of Health. Plans for allergy service improvement build on existing expertise in specialist allergy centres in Liverpool, Manchester and Preston.

The Network held a patient engagement event 'Shaping the Future of North West Allergy Services' on Saturday 26th June 2010 at the Warrington Rugby League Stadium. Working with the National Allergy Strategy Group, allergy patients, their carers and relatives from around the region were invited to an event that aimed to start an on-going dialogue with service users to ensure their views inform the future development of services in the region.

### 2.0 'Shaping the Future of North West Allergy Services' – event objectives

- 2.1 Timely communication of local service developments:** To communicate the recent progress and future plans (including full historical context) to establish services.
- 2.2 Education:** To provide patients, their carers and families with current information about allergy management.
- 2.3 Listening to patients' views:** To undertake structured dialogue (focus groups) with service users on areas of the project that can be shaped and/or influenced by their views and to provide opportunity for patients to pose questions to an 'expert panel' about issues relating to their condition and allergy services provided by the NHS in the region.
- 2.4 Audience/participant satisfaction:** To gain feedback from the audience and participants about the event.
- 2.5 Feedback:** To pledge to feed back to participants/audience about how their views have been heard and actions taken to address key issues.

### 3.0 Methods: How we listened to patients

#### 3.1 Information giving and focus group discussion

The event was designed to provide as much opportunity for discussion as possible. Allergy specialists and NHS managers from the North West Allergy and Clinical Immunology Network led three separate, structured discussions of 10 people about allergy management and opened up an informal 'question and answer' session to all participants.

#### 3.2 Questionnaire

All delegates were encouraged to complete an event evaluation questionnaire designed to capture feedback about the event; their contact details for future communication and their views about:





- **Allergy services:** 'If you were in charge, what would be your TOP THREE priorities to make NHS allergy care better near where you live?'
- **Patient information** 'What kinds of patient information would you like to see?'
- **Testing** 'Where would you want to get tested for allergy, and why?'
- **Managing allergy** 'What do you need to know to help you to manage your allergy better?'

## 4.0 Findings

### 4.1 NHS allergy services

*"I feel like all the doctors want to do is treat my symptoms when all I want to know is how to prevent them."*

*"My allergy was diagnosed 20 years ago and I still take the same medication."*

#### 4.1.1 Key themes from discussions:

- Parents and guardians of allergic children have struggled with a lack of general awareness of allergies in an educational environment and were keen to see more work to educate and train teachers, play ground supervisors and dinner ladies. Discussions also revealed that parents were less confident that their child's needs would be met outside their family circle.
- Adrenaline pen prescribing is variable outside specialist centres. A number of patients reported that their GP was reluctant, and in some cases refused, to prescribe replacements for unused, expired adrenaline pens.
- Adult allergy sufferers shared the view that the 'lack of public awareness of allergy' 20 years ago resulted in inadequate diagnosis or treatment then, and poor management of their allergy now.
- Participants wanted GPs and different specialists to 'think outside of their own specialty'. Currently there does not appear to be a unified approach across specialties when treating allergy.
- There was an understanding that allergy is generally not a high priority for GPs, but they need to be educated and individual local NHS organisations (currently called primary care trusts) need to push the allergy agenda.

#### 4.1.2 Feedback about NHS allergy service needs taken from evaluation forms:

- 1) More care in the community – improved GP knowledge and nurse-led clinics
- 2) Better links between asthma, allergy and skin specialists
- 3) Planned allergy reviews

### 4.2 Patient information

*“Food packaging is a nightmare. There needs to be a uniform approach.”*

#### 4.2.1 Key themes from discussions:

- Food packaging needs to be improved to include the likelihood of allergen content rather than covering statements such as: ‘cannot guarantee nut free’.
- There are many allergy myths, such as ‘allergy causes asthma’ and ‘people living in rural areas have more allergies’. More effort needs to be made by the media to communicate reliable messages based on fact.

#### 4.2.2 Feedback on key allergy patient information needs taken from evaluation forms:

- 1) Need to be provided with all the facts when diagnosed.
- 2) Signposting to accurate and reliable information for ongoing allergy advice and support.
- 3) Information about new treatments and side effects.

### 4.3 Allergy testing

*“People need allergy tests at their local GP surgery - appointments are more frequently available in the community.”*

#### 4.3.1 Key themes from discussions:

- Many people pay for expensive allergy tests when they should be signposted to NHS services.
- Many of the patients had not been re-tested in the past 10+ years.
- Many of the patients believed that allergy testing needed to be based in the community.
- Patients do not feel that GPs are able to help with questions relating to allergy test results.
- GPs offer differing levels of advice and refer patients for tests inconsistently.

#### 4.3.2 Feedback on key allergy testing needs taken from evaluation forms:

- 1) Testing should be available in the community.
- 2) Better support is needed at the time of giving test results.

### 4.4 Managing allergy

*“I’m allergic to life.”*

*“I take two anti-allergy tablets daily, but I have no idea what I am allergic to!”*



#### 4.4.1 Key themes from discussions:

- Prescriptions are expensive. Allergy patients have to pay to manage their symptoms which may lead to non-compliance – free medication would improve management.
- Patients reported that some GPs are reluctant to prescribe adrenaline pens.
- Lengthening adrenaline pen shelf life would cut costs and would make life easier, meaning fewer repeat prescriptions.
- Educating patients about allergy management is essential. This needs to be undertaken by a trained healthcare professional.
- Diagnosis is key to management, for example, patients need to know pollen type to help with management.

#### 4.4.2 Feedback on key allergy management needs taken from evaluation forms:

- 1) Being provided with information about the latest treatment and side effects.
- 2) Knowing where to go for information, help and advice if allergies change or worsen.
- 3) Understanding self-help options, e.g. changes to patient's home environment.

## 5.0 Conclusions and recommendations

The evaluation forms about the event show that participants enjoyed the discussions and had a positive experience. From the discussions, it would appear that patients perceive medical and nursing care for allergies in the North West as a 'lottery'. A standard patient pathway should be developed, publicised and adhered to by services throughout the patient journey to avoid duplication, confusion and in some cases unnecessary delay to treatment.

Limited access to allergy services in the region was a common discussion area. Patients see improvements to primary care services as a priority for the future. Equitable access to allergy tests, and up to the minute, evidence-based patient information are also high on patients' lists of priorities. They empower patients, giving them the confidence to manage their allergies, many of which are with them for life. It is hoped that the North West Allergy and Clinical Immunology Network incorporates feedback from patients in forthcoming primary care study days.

It is recommended that this event marks the start of a formal dialogue with allergy patients in the region and that regular communication is established and that the region's Allergy and Clinical Immunology Network considers how best to ensure that the patient voice is heard as services are planned, established and reviewed.



## Appendix D: Developing an allergy tariff structure

Early discussions following the commencement of the Department of Health allergy pilot project led to the North West Specialised Commissioning Group recognising that more realistic regional currencies were required to ensure the future sustainability of services. Over the past three years, the North West primary care trusts have invested more than £2 million to 'pump-prime' allergy and immunology services.

In most trusts providing allergy and immunology services, the coding of activity presents problems and, in the absence of appropriate HRGs, local tariffs had been negotiated with primary care trusts which were, in some cases, detrimental to the services. It is envisaged that pump-priming investments will be withdrawn as and when a suitable tariff structure is developed and agreed and that services would then be sustained by generating sufficient income through current activity and its growth.

The service at Preston had a particularly inadequate tariff and its continuation was under threat. The network and the specialised commissioners provided support to the service in persuading local commissioners to change to a more sustainable tariff which should ensure the sustainability of the service and allow it to address some of its serious staffing deficits.

Between June 2009 and October 2010, costing work was undertaken with all NHS trusts providing specialised allergy and immunology services to define accurate, fair and sustainable tariffs for specialised allergy services in the region, for both adults and children. Consensus was reached based on patients being 'banded' by complexity.

This involved working closely with clinical teams who undertook a data trawl of case notes to determine the banding of patients and a more granular, 'bottom up' costing exercise to determine the cost of procedures, the staffing resource and overheads, necessary to deliver services within each band.

In September 2010 the national PbR team included indicative mandatory tariffs in the 2011/12 national 'sense check'. Although both commissioners and providers of allergy and immunology services would welcome the introduction of a mandatory tariff, the North West Specialised Commissioning Group highlighted the extensive work that has been undertaken within the North West to plan for the future financial sustainability of specialised allergy and immunology services through activity-generated income. The Group also raised concerns that the proposed mandatory tariffs would present a significant shortfall to meet the essential costs required to deliver safe and sustainable tertiary allergy services. The average costs for the four bands are illustrated overleaf:

**Table 2: A comparison of North West regional allergy costs (£s) by band with proposed national mandatory tariffs for outpatient attendances, first and follow up**

	Adult NW average cost		Proposed national adult allergy tariff	Paediatric NW average cost		Proposed national paediatric allergy tariff
<b>Band 2</b> (consultation/advice on management + allergy tests)	187		195	198		294
<b>Band 1</b> (consultation/advice on management – no tests)	94	315*	94	151	255*	218
<b>Band 3</b> (consultation/advice on management + allergy tests + additional tests/advice (e.g. vitalographs)/OPD input from dietician)	320			275		
<b>Band 4</b> (consultation/advice on management + allergy tests + complex investigation/treatment e.g. OPD drug challenge/desensitisation/omalizumab injection)	376			400		

\*Weighted average cost of Bands 1,3 and 4

- Comparing average service delivery activity and costs with proposed mandatory tariffs (first and follow-up appointment) suggests that band 2 procedures are equivalent to the suggested mandatory 'first appointment'. The procedures undertaken in bands 1, 3 and 4 taken together did not equate to the proposed mandatory 'follow up' procedures and tariff, apart from band 1 itself which is an extended consultation only and, from our work, represents only a small proportion of the total follow up work.
- Further work is being carried out on this and may lead to a refining of the figures as well as the approach described above.



## Appendix E: Epidemiology

<sup>15</sup> *A review of services for allergy: the epidemiology, demand for and provision of treatment and effectiveness of clinical interventions*, Department of Health, July 2006.

<sup>16</sup> House of Lords Science and Technology Committee report on allergy, sixth report of the session 2006-7, September 2007.

<sup>17</sup> Gupta R. Prevalence of allergy in the UK. *Clin Exp Allergy* 2004; 34:520-526

<sup>18</sup> *Allergy: the unmet need. A blueprint for better patient care* – Royal College of Physicians Working Party on the provision of allergy services in the UK. Royal College of Physicians, June 2003.

In the Department of Health's 'A Review of Services for Allergy' in 2006<sup>15</sup>, it was concluded that in England:

- Very large numbers of patients are seen in primary care with conditions that may be allergic in origin. As many as 10 million people can be expected to self-manage their allergy or be treated symptomatically in primary care.
- 10 million people require an allergy diagnosis for effective care to be provided (up to 7.5 million of these may require some kind of specialist care).
- Demand for rhinitis and eczema care in general practice is not reducing.

The increasing number of people at risk of, and experiencing, anaphylaxis appears to be primarily a result of an increase in the number of people with specific food allergies.

In 2007 the House of Lords Science and Technology Committee report went further, stating that allergy in the UK had reached 'epidemic proportions', with services for allergy patients in the UK 'lagging behind' other parts of Europe<sup>16</sup>.

It was with this context in mind that key medical conditions associated with allergic and immunodeficiency diseases were identified by the North West's allergists and clinical immunologists at the beginning of the project. Incidence and prevalence data was then used to identify their impact in the population.

### Adults

Allergy epidemiology has been subject to stringent research in the UK for some years, producing high quality data. These have been reviewed<sup>17</sup> and, for example, show that allergy is common (up to 45% of adults) and expensive (allergy accounts for 11% of primary care prescriptions – costing £6.8 billion). There is also considerable consumption of non-prescription drugs (and, increasingly, non-prescription diagnostics) so the overall cost of care is thus far higher.

A closer look at allergy epidemiology identifies five factors which may impact on allergy service provision in the North West:

- **Allergy is over reported by patients**

When self- or parent-reported allergy is investigated using stringent tests (double-blind control challenge), typically only 30% of reported symptoms are found to have an allergic basis. This has two important implications in that epidemiological data need to be interpreted cautiously and that the greatest activity in any allergy service will be in the early referral stages rather than downstream. Hence, educational resources may be best focussed where patients initially seek advice.

- **The growth in allergy does not affect all conditions and all locations equally**

The Royal College of Physicians report 'Allergy: The Unmet Need'<sup>18</sup> summarises the very high prevalence of the chronic allergies (asthma, rhinitis and eczema) in the UK and increasing trends in the acute allergies (nut allergy, anaphylaxis and allergic reactions to drugs). This summary is



<sup>19</sup> Gupta R. et al. *Thorax* 2007; 62:91-96

<sup>20</sup> Anderson HR, *Thorax*, 2007

<sup>21</sup> Bjorksten B, *Paed Allergy Immunol*, 2008

<sup>22</sup> Kuehni CE, *J Allergy Clin Immunol* 2006

<sup>23</sup> Nielsen NM, Linneberg A, Menné T et al. *Br J Dermatol* 2002; 147:487-92

<sup>24</sup> Coenraads P-J, Diepgen T, Uter W et al. *Epidemiology*. In: Frosch PJ, Menné T, Lepoittevin J-P eds. *Contact Dermatitis*. 4th ed. Springer (Berlin) 2006:135-63

<sup>25</sup> Hellgren L. The prevalence of urticarial in the total population. *Acta Allergol* 1972, 27:236-240

<sup>26</sup> O'Donnell BF, Lawlor F, Simpson J, Morgan M, Greaves MW. The impact of chronic urticarial on the quality of life, *Br J Dermatol* 1997; 136:197-201

<sup>27</sup> Gaig P et al. *Epidemiology of urticarial in Spain J Inest Allergol Clin Immunol* 2004; 14 (3): 214-220

based on good evidence from cohort studies that the overall prevalence of allergy increased in the period leading up to the mid-1990s. This has been established for a wide range of allergies including peanut allergy, hay fever and eczema<sup>19</sup>. After the mid-90s there appears to be a divergence in UK allergy trends. For example, GP prescriptions for nasal allergy barely changed in the decade after 1992, whilst there was a ten-fold increase in prescribing for allergic emergencies. ICD data show that there was an increase in hospital admissions for anaphylaxis, whilst admission rates for other chronic allergies remained fairly stable. Recent data<sup>20</sup> go as far as suggesting the rate of new presentations of asthma have declined since 1992. Taken together, these findings have been interpreted as showing a flattening out of growth in the chronic allergies with a concomitant increase in acute allergies. The ongoing increase in anaphylaxis occurs in a heterogeneous group of patients (drug, food induced) and the increase in incidence has not been explained. The situation in low income countries appears to mirror the UK situation of 20 to 30 years ago<sup>21</sup>, although the data may not be robust. This may have implications for services in areas of recent high migration.

- **Allergy does not affect all ethnic groups equally**

The relative risk for self-reported allergy symptoms is 1.2 to 2.6 in non-Caucasian individuals. Parent-reported wheeze is nearly five times more prevalent in non-Caucasian children born in the UK and this risk is established early in life<sup>22</sup>. These ethnic differences in allergy risk appear to persist through the life of individuals born in the UK. Further research is required to confirm these findings. There are no data on how these differing needs are met by allergy services in the UK.

- **Contact dermatitis is common and causes significant disability and time off work**

Contact dermatitis accounts for 4–7% of all dermatological consultations<sup>23</sup> and in Europe the prevalence increased modestly from 15.9% to 18.6 % between 1990 and 1998. The incidence of occupational dermatitis in most western European countries is in the range of 0.5–1.9 cases per 1000 workers per year; skin diseases account for 13–34% of all occupational diseases and contact dermatitis constitutes 90-95% of these<sup>24</sup>.

- **Chronic urticaria is a common debilitating illness that may require expert care**

15-25% of the population experience symptoms of urticaria at some stage<sup>25</sup>. Chronic urticaria has a comparable impact on the quality of life to triple-vessel coronary artery disease<sup>26</sup>. The point prevalence of chronic urticaria in Spain was reported as 0.6% in 2004<sup>27</sup>.



### Children

Allergy is common, affecting around 1 in 5 children in the UK. Although allergic conditions are much more common in Western than Third World countries, there is no suggestion that their prevalence varies substantially within a particular country. The most common paediatric allergic diseases and their estimated prevalence in the UK, based on published data, are shown in the following table:

Common allergic diseases	% of children ever diagnosed with disease
<b>ACUTE ALLERGIES</b>	
Milk/egg allergy	6% of infants
Nut	1%
<b>CHRONIC ATOPIC DISEASES</b>	
Eczema/allergic dermatitis	15%
Asthma	10%
Hay fever/allergic rhinoconjunctivitis	20%

**Source:** The above information has been extracted from two unpublished adult and paediatric working group papers.





# Appendix F: Report on the Progress of a Project to Assess Adult Allergy Care in District General Hospitals in North West England

**Prof M G Pearson**

University of Liverpool

October 2010

**Aintree Health Outcomes Partnership @**



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### A. Summary

1. Allergy is common, comes in many different forms and can affect many different parts of the body. Asthma, Eczema and Allergic Rhinitis are three common examples of allergy affecting particular organs that are currently cared for more often by organ-based specialists than by allergy specialists. What implications should there be for the relationship between the established organ-based services and the tertiary allergy centres from improvements in the latter?
2. An electronic questionnaire was designed to ask consultants in ENT, Dermatology and Respiratory specialities about the facilities for, and some attitudes to, managing the allergic component of patients' conditions within their units. Lists of all specialists and their e-mails were established. Consultants were circulated with reminders via secretaries and e-mail and the results collated.
3. Response rates, despite the active reminders, were disappointing and much less than previous e-surveys run from the Clinical Evaluation Unit at the University of Liverpool when researching other conditions. One theory may be that the interest and importance of allergy to these organ-based specialists is less than had been expected.
4. Almost all units that responded had access to testing facilities to manage allergic disease so it should be possible to deliver the service (allergy diagnosis, treatment and management) from secondary care sites.
5. Between a third and a half of respondents claimed to have a personal interest in allergy (potentially biased by the low response rate, i.e. those with an interest were keener to respond). Fewer were offering specific allergen immunotherapy (desensitisation) for allergic rhinitis or asthma. However, most respondents thought such treatment should be available.
6. When faced with a difficult allergy-related problem, specialists were more likely to seek help within their own organ-based speciality than from a tertiary allergy service and most believe their secondary service is able to provide all that is needed. But, when invited to make suggestions on service improvement, there was much more interest in having additional allergy support, although most who answered wanted this support to be provided in their secondary care unit rather than in a tertiary centre.

### B. Comment

1. The low response rate demonstrates how much effort will be needed to engage those in clinical specialties currently in a position to provide specific allergy services for these three common, specific conditions. The respondents do not perceive there to be a marked shortfall in the current quality of care but would like some additional support locally if it were on offer.
2. Raising standards will require:
  - a) some demonstration or evidence that care is not adequate (e.g. similar to the national audit of stroke care)
  - b) development of specialist allergy expertise that is flexible enough to link directly with the secondary services and thus build on their organ expertise.

## 1. Background

- 1.1 Allergy is a general term encompassing a range of clinical syndromes and conditions that span most of the organs of the body and affect a substantial proportion of the population. These syndromes and conditions are managed variably by organ-based specialists, by primary care, by self care and by a small number of allergy specialists. Several reports (most notably the House of Lords Science and Technology Committee report on 'Allergy', 2007<sup>28</sup>), have suggested that the management of allergic conditions could be organised and delivered more effectively. In 2008, the Department of Health selected NHS North West as England's pilot Strategic Health Authority to develop ways by which improved care for patients could be achieved.
- 1.2 One of the central themes of the House of Lords report is that allergy is very common and allergy services are not available in proportion to need. Indeed, in most parts of the country, formal allergy services, where they exist at all, consist of small tertiary units and, although it is recognised that allergy is very common, there is no system for recognising or understanding the provision at secondary or primary care level.
- 1.3 Allergy services in the North West centre on tertiary allergy clinics in Liverpool, Manchester and Preston led by a mix of Allergists and Clinical Immunologists supported by specialist nurses. Local data from the North West Allergy and Clinical Immunology Network has already demonstrated that access to these tertiary clinics is variable across the region. The pattern of caseload in these centres is also unpredictable.
- 1.4 Three of the commonest allergic conditions are asthma, hayfever/rhinitis, and eczema. These conditions have traditionally been treated and managed by respiratory, ENT and dermatology specialists in secondary care working jointly with primary care. Rare and/or complex allergy accounts for a small proportion of referrals and may be referred for tertiary evaluation.
  - a. The current organ-based services in secondary care have evolved over the last 40 years. Allergy is a disease process usually affecting one part of the body and it is not illogical for specialists in that part of the body to take an interest in allergic processes as much as in the equally complex processes of carcinogenesis and chronic inflammation. The organ basis was probably cemented into place when topical steroids, i.e. steroids that can be inhaled onto internal surfaces or applied to the skin, arrived in the 1970s. These drugs revolutionised the management of some allergy-based conditions with a very low side effect profile. Because the drugs were so efficacious, the emphasis moved from attempts to diagnose and eliminate the cause of the allergy, toward assessing the levels of control that could be produced by the drugs. In that context, clinical interest in, and research studies into, the allergic basis of these disorders waned.



<sup>29</sup> British Thoracic Society and Research Unit of the Royal College of Physicians of London, 1990

- b. The national asthma guidelines (the first national UK guideline) in 1990<sup>29</sup>, described management shared between primary and secondary care and recognised the role of nurses as well as doctors in the regular follow up of patients. Many local services revolve around specialist asthma nurses (who have had additional asthma training) liaising with practice nurses and GPs. As local services they can take account not only of disease control but also the social, emotional and other aspects of patients' lives. Asthma control is not just about drugs but about the factors that enable patients to use (or to remember to use) those drugs regularly. Many practices include nurse-led asthma clinics as part of their service.
- c. These local arrangements are demonstrably effective and have improved asthma control over the past 20 years with a third fewer asthma deaths nationally and also fewer admissions, in spite of an increased prevalence. The local systems thus deserve support but the driving theory behind them is based on better drug control, rather than of considering possible allergic causes. If a problem required specialist referral, most would refer to the organ based specialist secondary care. Few in the asthma clinics would be aware of the option to consider the tertiary allergy service. Similar, but probably less organised, secondary – primary collaboration occurs for eczema and allergic rhinitis.
- d. Within each of the specialities, the total burden of allergy-related conditions is relatively small and the specialists will spend the majority of their working week managing other diseases within their speciality, e.g. cancers and other even more common chronic disorders.

### 1.5 National Guidelines

#### a. Asthma

Current national guidelines from the Scottish Intercollegiate Guidelines Network/British Thoracic Society<sup>30</sup>, concentrate on a symptom/physiological based diagnosis and therapy from inhaled steroids. Identification of allergens (triggers) and avoidance, where possible, is recommended but it has a relatively lowly place in the diagnostic process. And specific immunotherapy is "to be considered...." only "if a clinically significant allergen cannot be avoided".

#### b. Eczema

NICE has extrapolated its paediatric guideline to all ages in the Clinical Knowledge section<sup>31</sup>. Allergy features little in the document other than in recommendations to avoid provoking factors. Treatment concentrates on topical steroids.

#### c. Allergic Rhinitis

Perhaps because this is often a milder condition, there are no national guidelines from NICE – although there is one from Wales<sup>32</sup>. The UK emphasis in this and other documents is on the diagnosis and avoidance of allergy but caution is expressed in regard to desensitisation and specific therapies, eg Grasax, are not recommended on cost grounds. In contrast the US view is more positive to immunotherapy<sup>33</sup>.

<sup>30</sup> Scottish Intercollegiate Guidelines Network/ British Thoracic Society, 'British Guideline on the management of asthma', May 2008

<sup>31</sup> House of Lords Science and Technology Committee report on allergy, sixth report of the session 2006-7, September 2007.

<sup>32</sup><http://www.wales.nhs.uk/sites3/Documents/739/ALLERGIS%20RHINITIS%20GUIDELINES.doc>

<sup>33</sup> <http://www.aaaai.org/conditions-and-treatments/allergies/rhinitis.aspx>



- 1.6 Although allergic mechanisms play an important part in each of these common conditions the emphasis for both diagnosis and therapy is not on allergy. When allergens (triggers) are identified then avoidance is recommended but when drug therapy is required the emphasis is on topical steroids reflecting the good clinical results achieved over a number of years. This emphasis differs from that within the House of Lords allergy report.
- 1.7 Any attempt to work with existing specialties within the region to identify the causes of allergy associated with the conditions that they treat has to overcome the potential disinterest from specialists who see symptoms as having been controlled with little need to chase the allergy component and competition from other conditions that appear to be of 'more pressing' concern.
- 1.8 There have been discussions with clinicians and patients across the region and a number of initiatives are in place to improve access to allergy services for children and adults. One initiative was to commission some work to examine the current provision of allergy care beyond the North West Allergy and Clinical Immunology Network and set a baseline that would allow commissioners to evaluate service improvements and, thereby, assist the planning and commissioning of better services.
- 1.9 One of the aims of this project was to assess the nature of the organ-based allergy services in the secondary care units of the North West and to gain an idea as to how the region's allergy network might best support allergy service improvements outside its specialist allergy centres.

## 2. Methods

- 2.1 We identified 20 Trusts with respiratory services, 22 with ENT services and 16 with dermatology units and, within those, e-mail contacts for 84 respiratory, 79 ENT and 50 dermatology specialists, using a combination of sources including a limited download from the Electronic Staff Register.
- 2.2 A brief questionnaire was developed to understand the individual consultant's particular interests, the numbers of patients seen with allergic conditions, the facilities available for diagnosis, the need for further advice, including to where the consultants referred patients, and their feelings about what would most improve services for allergy.
- 2.3 This questionnaire was shared with North West Allergy and Clinical Immunology Strategy Board members, modified in response to replies, and then set out by e-mail with an attached interactive spreadsheet which permitted online or offline completion. Most answers could be selected from 'drop down' lists. Care was taken to ensure that e-mail addresses were current and appropriate using a variety of sources. In all the e-mails were issued three times. Where responses were not received recipient addresses and confirmation of delivery were checked. Follow-up calls were also made to stress the relevance and importance of the initiative.



### 3. Results

#### 3.1 Response rates

The returns from the three questionnaires were most disappointing.

There were 10 responses from 7 hospitals (32% of the hospital units) for ENT; 14 from 9 hospitals (58% of the hospital units) for Dermatology; 13 from 10 hospitals (50% of the hospital units) for Asthma. Several consultants responded for their unit but that still means that less than half of the Trusts replied.

#### 3.2 Staffing Questions

Medical staffing of these departments was strongly related to the size of the trust but it was noticeable that nurse support appeared to vary widely with no obvious logic. Some units in each discipline appeared to have much larger support teams but, with the small numbers of trusts responding, this has not been investigated further.

Indeed, all conclusions must be treated with caution because of the limited responses but, with that proviso, a summary follows.

#### 3.3 Access to Allergy Tests

All units were asked about access to skin-prick testing, to IgE and RAST tests. In addition they were asked about skin patch tests (dermatology only) and spirometry (respiratory only).

There was wide availability of allergy tests in most hospitals but there were a few 'smaller' units (1 Dermatology, 2 ENT and 1 Asthma) that claimed to have no access to skin prick testing (but in one case there were conflicting responses from the unit).

All were able to do IgE and RAST testing. All but one dermatology unit had skin-patch testing available.

One asthma clinic reported no spirometry (important for asthma management but not for the allergy component) although they believed most patients required it (astonishing in 2010!).

The diagnosis of allergic conditions depends on (a) the careful taking of the history and (b) the use of some specific tests. These tests are neither expensive nor new and a secondary unit providing an allergy service would be expected to have them available.

Most of the secondary hospitals do have the necessary facilities to provide an allergy consultation within their organ-based services for these common conditions.

#### 3.4 Speciality specific aspects

The next 3 sections are subdivided by speciality to consider whether the specialists thought they were providing an allergy service or if more help might be needed.

##### a) Dermatology

###### i) Allergy interest

9 of the 14 dermatologists claimed a personal allergy interest with 5 saying they had a significant semi-tertiary practice for such conditions.



**ii) Referrals of challenging cases**

When dermatologists wanted more help with difficult eczema, then 8/14 would refer small numbers of cases within the speciality [only one referred more than 1-6 per year].

Destinations included Great Ormond Street, Hope Hospital (3), Alder Hey and to a local colleague in the same unit.

9/14 would also refer a few patients to allergists – none at more than the lowest option offered i.e. 1-6 cases per year [Destinations RLUBH 4, Hope 2, Preston 1, MRI 1 and Whiston/BGH 1].

The other 5 made no onward referrals - note one doctor working in a hospital that also houses a tertiary allergy service does not refer anyone to it.

Only one dermatologist admitted referring patients for advice about an occupationally-related skin allergy.

**iii) Multi-system allergy**

Asthma, eczema and rhinitis may occur in the same patient – they are all part of the allergy related “atopic syndrome”. When there was overlapping asthma, rhinitis (ie potential for multiple allergies or a multi-system allergy) only 5/14 would seek allergy clinic support.

**iv) Open questions inviting comment on what should be in place for allergy if money was not a constraint**

In contrast to the apparent reluctance to refer cases for second, more expert opinions (described above), the dermatologists did have suggestions for opportunities for better services. These mostly point to expansion of existing services but there is a theme (repeated later in other specialities below) of wanting better collaboration with allergists and immunologists.

Examples included

*Better integration of dermatologists and immunologists/allergists - citing recent exciting work on peanut desensitisation. More understanding of what an adequately staffed allergy service could contribute for a patient with a skin complaint.*

*A combined clinic with an immunologist possibly monthly and similar combined paediatric clinic.*

*Food ingestion testing.*

*Expansion of the paediatric dermatology service.*

*There is a view that all eczema/urticaria is due to allergy.*

*Patients with complex allergies, ie oral allergy syndrome/food anaphylaxis/protein allergy, need expert opinion and as dermatologists we do not have the training/facilities to deal with these problems.*



*At present the patch test clinic is running well and the waiting list is not excessive. The Allergy Clinic which is the province of the Allergist/ Immunologist may need extra support.*

*Better access to specialist allergy clinics.*

*Better integration of dermatologists and immunologists/allergists. Recent exciting work on peanut desensitisation for example. More understanding of what an adequately staffed allergy service would contribute to a patient with a skin complaint.*

### b) Asthma specialists

#### *i) Allergy interest*

10/14 asthma specialists reported getting referrals from a wider area with 5 claiming a semi-tertiary practice. These are perhaps a more specialised subgroup of respiratory specialists than would be generally expected, ie we have some potential selection bias in the answers.

#### *ii) Onward referral of difficult asthma*

13/14 would refer small numbers to recognised asthma super-experts – the exception is an expert.

5/14 would refer a few cases (1-6 patients/year) to the allergy units.

4/14 would refer some patients to occupational experts.

#### *iii) Specific services - Use of Omalizimab*

This is an expensive new product specifically for allergen-related asthma for which use is being “controlled” by commissioners. Although this is not easy to use, there is not a co-ordinated approach in place.

Of the 13 specialists

2 say they are free to supply it

5 can do so with specific permission from commissioners

7 have to refer – but refer to asthma rather than allergy specialists.

#### *iv) Use of desensitisation therapy*

This is a technique specific to allergy that fell out of favour in the 70's but is regaining credibility and features in current SIGN/BTS national guidelines.

Only 1/14 consultants offers this routinely and 2 would do so occasionally.

Most do not offer a service. None of the 3 offering the service is part of the tertiary allergy services but the one offering it regularly would be considered an asthma allergy expert by the respiratory community.





v) *Open questions inviting comment on what should be in place for allergy if money was not a constraint*

Responses were of two types

- support for having an allergy service was strong – but with a wish for it to be based in secondary sites rather than in a tertiary centre and
- support for more local asthma services

There was most enthusiasm (12/14 specialists) for desensitisation and immunotherapy to be available; 7 would want an allergist to provide it and 5 stipulated that it should be from within the secondary care unit.

Other comments included

*More general allergy input - probably a joint type clinic with asthma and allergy specialists.*

*A visiting Clinical Immunologist who would support both allergy and other aspects of clinical immunology, eg immunodeficiency syndromes.*

*Dedicated respiratory allergy clinics as stand alone rather than as part of our complex asthma service.*

*Specific occupational challenges.*

*Induced Sputum and Bronchial Thermoplasty and Joint ENT clinic. Also need psychologist dedicated to airways disease and dietician dedicated to airways disease.*

*Dedicated anaphylaxis pathway within hospital. Hayfever service with combined ENT/Respiratory input.*

*Skin test service.*

c) ENT specialists

i) *Allergy interest*

3/12 ENT surgeons professed personal interest in allergy with 5 more saying they had a colleague who provided this.

ii) *Onward referral practice*

10/12 ENT surgeons thought they provided a complete rhinitis service and only one admitted referring allergy problems onwards. None felt the need to refer outside their hospital for coexisting asthma or eczema.

However, in a later response, 6 did admit referring a few patients onwards for allergy/immunology advice (London 1, Newcastle 1, Preston 3, internal 1).



### *iii) Use of desensitisation therapy*

Desensitisation for hayfever/rhinitis is a well-established option and all but one respondent felt it should be on offer. However, only one was offering desensitisation routinely, although 2 more would do so occasionally. But 6 felt it should be a service offered from their clinic. 2 specifically stated that they would like an allergist to provide it but their hospital is not a tertiary centre.

### *iv) Open questions inviting comment on what should be in place for allergy if money was not a constraint*

No ENT specialists expressed a desire for a tertiary allergy service but there was interest in setting up more local services.

Specific suggestions included:

*Additional allergy/immunology consultant staff and associated nursing clinic support to run joint a clinic (combining paediatrics and adults if necessary).*

*Funding for sublingual grass pollen desensitisation, aspirin desensitisation, objective testing sense of smell, etc.*

*MDT clinic setup with some outreach/education role into community.*

*An allergy specialist on site.*

*A nurse practitioner and an ENT consultant to be appointed with a special interest in allergy providing desensitisation treatment.*

*A joint clinic with respiratory physicians.*

*Skin prick testing.*

*Increase specialist nursing input, undertake diagnostics in primary care, run combined clinics with dermatologists and allergists, train myself further, identify a big GP practice in the area and work with them.*

## **4. Comments**

### **a) Response rate**

The low response rate to the electronic questionnaire was a surprise and a disappointment. In comparison with responses to two longer electronic questionnaires sent recently from the Liverpool unit to all gastroenterologists and to all renal physicians in England about their NHS practice, this was **much** lower. The low response rate was despite actively chasing up contacts about the allergy questionnaire with telephone reminders to the specialists' secretaries and by further emails. Even with an explanation that service changes might happen without their input, there was still a lack of response.

There are no direct data on the non-respondents but we speculate that allergy is of less immediate concern for these organ-based specialists – probably because allergy forms such a relatively small part of the total workload performed by these specialists. This is a significant challenge for the implementation of any allergy strategy across the region and if the relative disinterest in secondary care is mirrored in primary care, implementation of an allergy framework will not be easy.



## **b) Capability of the services currently provided**

The organ-based specialists are managing patients with asthma, eczema and allergic rhinitis and make relatively rare use of specialist allergy advice. Most have the common allergy tests available within their secondary units and many of the clinicians clearly believe they are already supplying a service to their locality.

However, asked what they would like to have available, a significant number of these same specialists suggested that having a specialist allergist or immunologist within their trust would be desirable. This suggests that there may be some recognition of unmet needs – even though they are not campaigning for such additional help.

## **c) Is there a need for a tertiary service?**

### *i) Referral to tertiary centres*

There is an imbalance between secondary care specialists wanting to refer patients for allergy expertise and the availability of that service. This may partly explain the apparent dichotomy in which a few specialists refer a few cases to the tertiary units and the relative enthusiasm for having additional support in allergy.

Current practice is that when help is required with a difficult case, organ-based specialists are more likely to refer to another organ-based colleague than to the tertiary allergy service. This may in part derive from the success of topical steroid drugs in controlling most symptoms that has led to the ignoring of possible allergen avoidance or anti-allergy therapies. But it may also reflect the limited size of the tertiary allergy service such that it is difficult to obtain a quick referral.

However, when the doctors were given the opportunity to say what they would like to happen – their comments are supportive of establishing more allergy specialist services. The desire is however to have those services available within the secondary sector and not in tertiary centres.

### *ii) Desensitisation*

This is a long established therapy for rhinitis and gaining interest again for asthma. It is used less often in the UK than in the US and this reflects the very cautious approach in UK guidelines. There are few good trials and there was adverse publicity in the early 1980s with some high profile deaths in primary care.

These efficacy concerns led to it being abandoned in favour of simply treating with more topical steroids.

But it is being offered in a few units, even though, in asthma, this is from a hospital without a recognised tertiary allergy service [a personal interest of a (very good) respiratory specialist].

Despite the cautions, most of the clinicians in each of the specialities felt that this is a service that should be available – but preferably more locally than from a tertiary unit.



### 5. Conclusions

- 5.1 Allergy does not appear to feature highly in the minds of many secondary care clinicians and thus the implication of the House of Lords report is probably correct – allergy does not received the attention it deserves.
- 5.2 Many if not most organ based specialists, treating conditions that have an underlying allergic basis, are managing those conditions with relatively little support from the tertiary allergy specialist services. This pattern of service delivery stems from the demonstrable success of topical steroid treatments that is reflected in UK guidelines that emphasise steroid therapy compliance and links with primary care.
- 5.3 Given treatment guidelines that give only modest encouragement to allergy modifying therapies, and a practice (habit) of not referring for diagnostic or therapeutic advice, the task of persuading specialists and trusts to take allergy seriously is likely to be much bigger than was expected and will require more than simple exhortation from the centre.
- 5.4 If a tertiary service (of appropriate size) is to be set up in the NW, it may have a tough time attracting referrals and building links with secondary clinicians who believe they are already providing such a service. It may be that a care model of parallel clinics with visiting specialists (rather like the radiotherapy units provide), would be most likely to be welcomed.
- 5.5 Setting up a tertiary/secondary service would still not address the many patients still in primary care – but at least services from the secondary sites do have established links with primary care clinicians – nurses, doctors and others and thus are closer to the patient.
- 5.6 The greatest benefits are likely to be in more accurate diagnosis and thus more focussed therapy but benefits may not be apparent for some years. An asthma patient may be helped to have fewer attacks and thus to deteriorate less over a decade but, unless they were having multiple admissions (and most are not), this would not result in any short term cost savings for the NHS.

#### Mike Pearson

Professor of Clinical Evaluation  
University of Liverpool

20 October 2010

# Appendix G: Membership of the North West Allergy and Clinical Immunology Network Strategy Board

The Network Strategy Board was initially chaired by the North West lead PCT Chief Executive for Allergy and Immunology, Dr Leigh Griffin, from NHS Sefton. He was succeeded by Dr Julie Higgins, then Chief Executive of NHS Heywood, Middleton and Rochdale, and now Director of Commissioning for the Greater Manchester PCT Cluster.

The role of the lead Chief Executive as Chair was to oversee the work plan and provide additional assurances to the NWSCG on the progress of the project, as well as acting as a 'champion' for allergy and immunology in engaging fellow North West PCT Chief Executives in considering the future development of these services.

Board Role	Name	Organisation
Allergy and immunology Executive Lead (PCT Chief Executive)	Dr Julie Higgins	NHS Heywood, Middleton and Rochdale
Adult allergy sub-group clinical lead	Dr Tina Dixon	The Royal Liverpool and Broadgreen University Hospitals NHS Trust
Adult immunology sub-group clinical lead	Dr Hana Alachkar	Salford Royal NHS Foundation Trust
Paediatric allergy sub-group clinical lead	Dr Peter Arkwright	Central Manchester University Hospitals NHS Foundation Trust
Paediatric immunology sub-group clinical lead	Dr Peter Arkwright	Central Manchester University Hospitals NHS Foundation Trust
Immunology laboratories sub-group clinical lead	Dr Anthony Rowbottom	Lancashire Teaching Hospitals NHS Foundation Trust
Associate Director (Strategy), NWSC	Mr Roy Dudley-Southern MBE	North West Specialised Commissioning Team
NW Allergy and Clinical Immunology Project Manager	Mrs Louise Sinnott	North West Specialised Commissioning Team
Academic allergist	Professor Adnan Custovic	University Hospital of South Manchester NHS Foundation Trust
Paediatric allergist from the other tertiary service	Dr Aideen Byrne	Alder Hey Children's Hospital NHS Foundation Trust

Continued overleaf...

Board Role	Name	Organisation
Adult immunologists from each of the other zones	Dr Jim Darroch	The Royal Liverpool and Broadgreen University Hospitals NHS Trust
	Dr Matthew Helbert	Central Manchester University Hospitals NHS Foundation Trust
	Dr Pavaladurai Vijayadurai	Lancashire Teaching Hospitals NHS Foundation Trust
Paediatric immunologist from the other tertiary service	Dr Andrew Riordan	Alder Hey Children's Hospital NHS Foundation Trust
Academic immunologist	Dr Peter Arkwright	Central Manchester University Hospitals NHS Foundation Trust
Representatives of clinicians from other specialties who have a special interest in allergy	Dr Sacha Marsland/ Dr Jason Williams (dermatology)	Salford Royal NHS Foundation Trust
	Dr John de Carpentier (ENT)	Lancashire Teaching Hospitals NHS Foundation Trust
	Dr Angela Simpson (respiratory)	University Hospital of South Manchester NHS Foundation Trust
Adult immunology nurse representative	Mrs Alex Farragher	Central Manchester University Hospitals NHS Foundation Trust
Adult allergy nurse representative	Representation will be shared by one of the following representatives: Sheena Hopkins	The Royal Liverpool and Broadgreen University Hospitals NHS Trust
	Fiona Chew	The Royal Liverpool and Broadgreen University Hospitals NHS Trust
	Debbie Hughes	University Hospital of South Manchester NHS Foundation Trust
Paediatric allergy nurse representative	Mrs Chris Doyle	Alder Hey Children's Hospital NHS Foundation Trust
	Mrs Sarah Allatt	Central Manchester University Hospitals NHS Foundation Trust
Paediatric immunology nurse representative	Mrs Barbara Boardman	Central Manchester University Hospitals NHS Foundation Trust
Primary care commissioning representative	Marie Clayton Scheduled Care Development Manager	NHS Salford
Primary care healthcare professional with an interest in allergy	Dr Ali Majid/ Dr Luke Twigden	NHS Bolton NHS Stockport
NHS North West (NWSHA) representative	Not identified	NHS North West
Patient/carer representative	Sue Hunter	Asthma UK



# Appendix H: Generic allergy care pathways

<sup>34</sup> Royal College of Paediatrics and Child Health, 'Care pathways for children with allergies', <http://www.rcpch.ac.uk/child-health/research-projects/care-pathways-children-allergies/care-pathways-children-allergies>

There was a consensus among clinicians within the region that it would be helpful to describe those services which should be developed within the different levels of paediatric allergy care. These generic pathways were developed by the working groups of the North West Allergy and Clinical Immunology Network Strategy Board.

Disease-specific pathways were developed by the Royal College of Paediatric and Child Health<sup>34</sup>, involving some North West network members.

## For children

**Tier 1** - Most general practitioners prescribe for children with allergies but may seek guidance on the specific conditions.

**Tier 2a** – Children with acute allergic diseases may need to access local accident and emergency services, and may be referred to a local general paediatrician with no special expertise, or to a dedicated allergy clinic in order to confirm diagnosis and receive advice about the management plan, taking into account local arrangements.

Where appropriate local expertise in treating the condition is lacking, or where the patient does not respond to standard therapy, they should be referred on to a tier 2b or tier 3 paediatric allergy service.

**Tier 2b** – This is based on a general paediatrician with an interest in allergy, working in a local district general hospital and running a dedicated allergy clinic there. This is supported by a tertiary paediatric allergy specialist visiting on a monthly basis and is referred to as a 'District Paediatric Allergy Centre'.

**Tier 3** – 1-2% of children with allergies may need to be seen by specialists. Many of these should require only a single visit rather than regular follow-up, provided that there are local allergy clinics in place.

In a proportion of cases, management may be just as effectively carried out by clinicians from other paediatric specialties such as dermatology, respiratory medicine, ear, nose and throat, gastroenterology and ophthalmology. In most cases the tertiary review of patients should not be necessary once the diagnosis and management advice are in place and follow-up can be undertaken by the GP or at the local hospital.

## For adults

The purpose of describing the role of the different levels of care within the adult pathway is to provide clarity about what care should be delivered at a particular level. It was felt that there was a lack of knowledge and confidence among clinicians, particularly at primary care level, about making referrals into allergy services, the reasons for this being a possible lack of training in allergy and/or a lack of awareness about where specialist services and expertise were located within the region.



### **Primary care role in the management of allergy**

- Manages urticaria in primary care and refers when symptoms remain intolerable despite following advice in regional protocols.
- Refers rhinitis patients to secondary care services when medical treatment has been optimised as much as possible according to regional allergy management protocols but is not proving to be effective.
- Responds to ACE-induced angioedema appropriately.
- Writes adequate referral letters e.g. for antibiotic allergy.
- Refers appropriately for reactions to latex.
- Recognises the signs and symptoms of contact dermatitis and refers to a local secondary care dermatology service.
- Recognises the signs and symptoms of atopic eczema and refers to a local secondary care dermatology service.
- Manages asthma in primary care and refers when appropriate.

### **Secondary care role in the management of allergy**

- Screens and investigates rhinitis – may refer on if immunotherapy indicated.
- Screens and investigates latex allergy – may refer on to contact dermatitis service and allergy service for type 1 immediate reactions.
- Screens and investigates asthma – may refer on to specialist respiratory service.
- Screens and investigates eczema – may refer on to contact dermatitis service.
- Responds to enquiries about ACE-induced angioedema.
- Assesses and manages contact dermatitis and, where appropriate, refers on to tertiary service for patch testing.

### **Tertiary care role in the management of allergy (this varies between centres, dependent on clusters of expertise in the region)**

- Screens and investigates complex drug and vaccine reactions (CMFT, RLBHHT, LTHTR, UHSM, SRFT)
- Provides anaesthetic allergy clinics (CMFT, RLBHHT, LTHTR, UHSM, SRFT)
- Offers a refractory urticaria service. (SRFT)
- Offers aeroallergen and venom immunotherapy (CMFT, RLBHHT, LTHTR, UHSM, SRFT)
- Provides food challenge and dietetic advice (CMFT, LTHTR, UHSM, SRFT, RLBHHT)
- Offers patch testing for contact dermatitis (SRFT, RLBHHT)
- Investigates and manages multi-system allergic disease (CMFT, RLBHHT, LTHTR, UHSM, SRFT)

#### **Key:**

CMFT: Central Manchester University Hospitals NHS Foundation Trust; RLBHHT: Royal Liverpool and Broadgreen University Hospitals NHS Trust; LTHTR: Lancashire Teaching Hospitals NHS Foundation Trust; UHSM: University Hospitals of South Manchester NHS Foundation Trust; SRFT: Salford Royal NHS Foundation Trust.







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## North West Allergy and Clinical Immunology Network

*Quayside  
Wilderspool Park  
Greenalls Avenue  
Stockton Heath  
Warrington  
WA4 6HL*

*Tel: 01925 406017  
Email: [info@nwsct.nhs.uk](mailto:info@nwsct.nhs.uk)*

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