

# 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

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# Foreword

This report gives an update on changes to allergy service provision following the 2007 report of the House of Lords (HoL) Science and Technology Committee's inquiry into allergy.

A joint Working Party of the Royal College of Physicians (RCP) and Royal College of Pathologists (RCPath), supported by the British Society for Allergy and Clinical Immunology (BSACI) was established in May 2009, with a remit to collate evidence of progress in implementing the HoL committee's recommendations. We were keen to ensure full engagement of patient societies in order to collate their views, and to solicit feedback on changes to the experience of patients who are using the services. The report focuses on development in England and Wales but, where relevant, we utilise evidence from Scotland. The recommendations of the HoL report are given, followed by the progress update relating to the recommendations.

Evidence from the Department of Health (DH) in November 2009 provides an update to the government's response to the House of Lords Science and Technology Committee Report on Allergy – 6th Report of Session 2006–7 (Cm 7255), and coordinates the responses of 20 contributors.

In 2008, the DH called for a strategic health authority (SHA) to pilot improvements in allergy services, with a view to rolling them out nationally if successful. A small amount of funding was awarded to the North West Strategic Health Authority (NWSHA) for this purpose. Notably, however, some other regions have made progress without targeted funding or directions to commissioners, such as in Wessex, north and south London, Yorkshire, East and West Midlands, and Northern Ireland. We comment on the plans of the NWSHA pilot project against the recommendations, but we have not formally evaluated the pilot; this is the responsibility of the DH.

Many UK consultants in allergic disease have come into the field through a variety of specialty training routes. Some had no formal training in allergy, but have developed current training programmes. They are on the specialist register of their parent specialty, and some are recorded as 'allergists'. We therefore use the term 'allergy specialist' to cover those expert senior doctors who work principally with patients with allergic disease, maintain their continuing professional development, and research in allergic disease.

The financial future for the health service is currently uncertain, and very different from the climate in which the original HoL report was written. Services like allergy, which have been chronically under-resourced and under-supplied in the UK compared with the rest of Europe, are especially vulnerable and must be protected.

Overall, we conclude that leadership is essential for allergy services to develop and to begin to attain the level of service that is available in most of Western Europe. This leadership needs to be at regional level, wherever possible, although more local leadership is also required. This leadership should come from clinicians whose work revolves around allergic disease. This will then allow education and training initiatives to develop and foster research, especially translational research in academic centres within the region.

The full evidence is available as a PDF appendix to the report.

# Acknowledgements

We are grateful to the Royal College of Physicians and the Royal College of Pathologists for their support in establishing the committee, and to the British Society for Allergy and Clinical Immunology, who provided additional funding for the committee secretariat to be provided by the Royal College of Physicians. We also recognise the important input from the Royal College of General Practitioners and the Royal College of Paediatrics and Child Health.

We recognise the importance of the patient expertise in managing allergy, and we are grateful to all those patient groups who contributed through the Patient and Carer Network Committee that we established, so ably chaired by Suzie Hughes. Members of this group were from: Allergy Action, Allergy UK, The Anaphylaxis Campaign, Asthma UK, Latex Allergy Support Group, The National Allergy Strategy Group, the National Eczema Society, and Skin Care Campaign.

We are grateful to the Royal College of Physicians for administrative support.

We are particularly grateful to Dr Bill Egner for his tireless work in collating all the material for the committee, and for his work on this report.

# Conflicts of interest

Dr Bill Egner is also Director of the UK National External Quality Assessment Service (UKNEQAS) for Immunology, Allergy and Immunochemistry.

# I Executive summary

## Recommendations for action

This report recommends that further actions are needed from the Department of Health (DH), primary care trusts (PCT), local health boards (LHB), strategic health authority (SHA) commissioners, providers of allergy services, and patients, in order to provide cost-effective improvements in allergy care, despite the current funding crisis.

We emphasise the need for better allergy services and more allergy specialists (which has not yet been addressed), but also the importance of ensuring that all existing services are identified and supported in the interim, by enhanced interaction with allergy specialists.

We highlight the depth of commitment from managers, physicians and nurses, to the provision of better care for patients with allergic disease, and the untapped well of support and input which can be provided by patient organisations to enhance existing care and to design service improvements.

We highlight the real practical difficulties in engaging multiple providers and commissioners on a service improvement project which lacks appropriate drivers, such as DH direction/facilitation or incorporation into Quality and Outcomes Frameworks (QOF).

We recommend that the DH designate a single lead SHA, acting as a national resource to collate and coordinate the improved networking and service evaluation of all the regional allergy services and networks. We recommend that each SHA should ensure that PCTs support initiatives to improve allergy care in collaboration with local hospitals, to improve the provision of care closer to home, and to support their general practitioners, consultants and nurses in delivering the best possible care in the most effective way. The House of Lords (HoL) model of multi-disciplinary allergy services, led by allergy specialists, remains the recommended model, adapted to local circumstances. Local initiatives to work towards this should be supported.

We highlight how far the individual initiatives deviate from the ideal recommendations of the HoL report, and the lack of validated outcome measures or service accreditation standards which would allow improved measurement of the need and the quality of services provided. Initiatives from the Joint Committee on Immunology and Allergy of the medical royal colleges, as well as other professional societies and services, have initiatives to develop such measures and standards, and to share protocols and good practice. Further development and validation of these initiatives should be supported.

We emphasise the key role of professional leadership from physicians, professional organisations and medical royal colleges in developing such mechanisms to evaluate service quality and supporting improved service provision. We recommend that this group reconvene in 2–3 years to ensure progress.

### Conclusions

The financial future for the health service is set to be very different from the climate in which the HoL report was written. A specialty like allergy, which is currently under-resourced and under-supplied, is especially vulnerable and must be protected. The quality of existing patient services in allergy can be improved by expanding allergy specialist leadership.

Progress against the recommendations of the HoL report has been notable in several areas:

- ▶ The withdrawal of inappropriate dietary advice to pregnant women has occurred.
- ▶ There has been widespread adoption of projects by the National Institute for Health and Clinical Excellence (NICE) for short guidelines on diagnosis and assessment (but not management) of food allergy in children and venom immunotherapy.
- ▶ There is ongoing, if limited, development of paediatric care pathways.
- ▶ There has been a small attempt to address the lack of trained allergy specialists (resulting from initiatives prior to the HoL report), through an additional five allergy and five immunology medical training posts. However, this has not addressed the long-term succession planning and manpower problems, since this totals only 12 adult and three paediatric UK allergy trainees.
- ▶ A pilot allergy centre in the North West region has been established, but:
  - This is in the early stages and the governance and evaluation strategies remain to be developed. The final phase of evaluation should take place when the service has had time to be firmly established.
  - The North West centre model deviates from the HoL model in some respects, as it appears to be a loose network rather than a clustering of services in a managed clinical network with clear leadership in allergy.
  - Limited numbers of new appointments have occurred.
  - There is no funding to monitor the outcomes effectively.

For many other recommendations, progress has been slow and non-existent:

- ▶ The appointment of allergy specialists to lead multidisciplinary teams in each SHA has been insufficient to meet the clinical need and training requirements of other healthcare professionals.
- ▶ An allergy specialist with a clear remit to lead effective networking of services should be empowered to instigate change across each regional cluster of services by colleagues, PCTs and trusts. A designated clinical lead role should be developed.
- ▶ Improvement and rationalisation of useful and non-defensive food labelling has not been adopted.
- ▶ Lack of reliable NHS data on services or workload and inadequate coding persists.
- ▶ Patient engagement remains underutilised and should be strengthened. This should be improved both at local level with service providers, and at a regional level for networks, PCTs and SHAs, including the national lead SHA.

- ▶ There has been little progress on improving governance and training in the management of allergic disease in primary and non-specialist services, or in the clinical governance of complementary practice.
- ▶ Evaluation of immunotherapy for inhaled allergens by NICE has not occurred.

Two areas have fallen outside the remit of this committee:

- ▶ Provision of generic adrenaline auto-injector prescriptions in schools requires a change in legislation.
- ▶ Evaluation of complementary and alternative therapy has been in part addressed in a House of Commons Science Committee Evidence Check on Homeopathy, which reported in February 2010.<sup>1</sup>

Some optimisation of existing services and clustering of specialist services is evident. Around the UK, some changes have occurred to make best use of existing services by allergy specialists and other specialties. A considerable will to improve specialist allergy care exists across multidisciplinary boundaries, particularly in dermatology, immunology, otolaryngology, respiratory medicine, and paediatrics. The few specialists in occupational allergic disease, although motivated, are often working outside the NHS; managerial and financial constraints have impeded multidisciplinary interaction. SHAs must take a lead to ensure that these networks evolve, interact and strengthen, and this process could be guided and enhanced by the appointment of a single lead SHA.

## Areas of concern

Funding agreements for services as laid out by PCTs and LHBs often have an unclear framework; the quality of commissioning needs improving to ensure that the quality of services is enhanced and clinical leadership strengthened, as envisaged by Lord Darzi.<sup>2</sup>

Some 'point of care' allergy tests are inappropriate. PCTs and LHBs, through their pharmacy officer, must ensure that community pharmacy allergy testing is included in clinical governance processes, with clear accountability, quality assurance of training and service delivery, and development of appropriate expertise. Such tests should be externally quality assured for both diagnostic methodology and the interpretation of results.

There is little improvement on the ground perceived by patients or professional groups. A repeat survey of GPs reported no improvement in access to specialist service provision.<sup>3,4</sup> This lack of progress is partly due to:

- ▶ slow implementation of the HoL recommendations
- ▶ lack of investment in allergy services
- ▶ inadequate networking and lone working – there is evidence of isolated subspeciality practice in allergy which is ripe for improvement
- ▶ a lack of the critical mass of staff (both specialist and non-specialist) to deliver the objectives by improving service efficacy
- ▶ little access to and underutilisation of immunotherapy, with wide geographic variations.

The quality and efficiency agenda can be supported by ‘smarter’ working, despite the increasingly devolved NHS and the paucity of specialists to provide clinical leadership. This could enhance quality using multidisciplinary resources and improved networking, but needs clear leadership from allergy specialists. Clustering of services (some are in the early stages) should be progressed where centres are currently impractical. The NHS can ‘invest to save’ by appointing a lead consultant allergy specialist to improve cost-effective service provision and enhance quality. This will:

- ▶ lay the foundations for appointment of allergy specialists in each SHA to provide leadership across a geographical area
- ▶ create a managed clinical network
- ▶ ensure care meets agreed national best practice standards
- ▶ enhance sharing of good practice
- ▶ improve and accredit allergy education
- ▶ improve cost-efficacy
- ▶ facilitate implementation of care pathways/care bundles
- ▶ improve audit of patient outcomes and satisfaction with care
- ▶ enable service accreditation to monitor and enhance the standard of care
- ▶ encourage leadership and identify subspecialty service champions
- ▶ facilitate effective engagement with patient groups
- ▶ facilitate proper coding, accurate workload and quality of service data
- ▶ enable more effective specialised commissioning.

NHS Evidence, responsible for e-learning, should consider providing training packages in allergy for GPs and nurses in primary and community care, including school nurses.

### Model of service configuration

We concluded that no one model should be imposed over others. However, some core principles must be in place to ensure equity of access to specialist services across the UK, in order to reduce mortality and morbidity by accurate diagnosis and appropriate management of allergy, particularly in complex multi-system manifestations. These core principles include:

- ▶ clear clinical leadership for allergy services across a defined geographical area
- ▶ clustering of specialist services to serve a defined population
- ▶ explicit funding agreements for allergy services that encompass the need to:
  - develop patient pathways from primary to secondary care
  - provide local advice and education to other services in primary and secondary care
  - improve immunotherapy services

- share protocols and guidelines at a national level with other providers
- engage with patient groups to plan and evaluate services
- code their activity for contract monitoring and for clinical audit
- work within an agreed governance framework
- maintain the team’s continuing professional development, focused on allergy
- be registered and accredited through an appropriate mechanism.

SHAs must communicate together about the allergy services in place, to ensure that there is access to appropriate referral services for complex conditions, such as adverse reactions to anaesthetic agents.

## Conclusion

Progress to improve allergy services to patients will be optimised by having a cohesive group which represents all aspects of allergy and immunology, empowered to take the strategy forward both nationally and locally.

This group must have clear leadership and clarity of purpose, and must work across historic specialty/professional boundaries.

## 2 Allergy services: a survey

### Allergy services survey via the professional societies

A standardised survey was instigated by the committee and circulated to: respiratory physicians; immunologists; allergists; anaesthetists; occupational health physicians; ear, nose and throat (ENT) physicians and surgeons; paediatricians and dermatologists, to determine how much allergy activity is currently being undertaken. Many services deal with a limited range of allergic disorders. Services provided by ENT surgeons relate mainly to rhinitis, and 50% have no allergy training. Respiratory services relate primarily to asthma, and dermatology to eczema, angioedema, contact dermatitis and urticaria. Clinical time spent delivering allergy services was typically 80% for a paediatric allergist, 100% for an adult allergist, and between 5 and 70% for other specialities. The tables show that specialists are inadequate in number and available time to devote to allergy, but there is a potential for existing services to network better to enhance service quality, led by an allergy specialist. No current mechanisms exist to evaluate service quality against agreed criteria. The data do not distinguish centres where multiple specialists work together in the same service. Thus, adding up the number of sites will overestimate service provision.

### Networks

There is evidence of many local educational activities, but little evidence of sharing of expertise, or of coordination. Several groups expressed an interest in, or potential for developing into a HoL cluster, but resource implications were highlighted. Patient involvement appears rare.

At least 10 existing networks were identified which include or focus on allergic diseases:

- ▶ Trent Immunology and Allergy Consortium (TRIAC)
- ▶ West Midlands Allergy Group
- ▶ South East Immunology Network
- ▶ Wessex Allergy Network
- ▶ South West Group
- ▶ South Yorkshire and Yorkshire Paediatric Network
- ▶ Allergy Nurse Specialists in Eastern Region
- ▶ London Allergy Group
- ▶ London Paediatric Allergy Group
- ▶ Paediatric Allergy Group North London with a base at St Mary's Hospital (part of Imperial College Healthcare NHS Trust).

Table 1 England and Wales: consultants/sites providing adult services

Main specialty	Number of hospital sites	Number of consultants	Number of sites with unselected allergy clinics as per NSSDS for allergy*	Consultants with subspecialty clinics <sup>†</sup>	Number of centres coding as allergy 317	Networked with others <sup>‡</sup>	Multi-disciplinary working <sup>§</sup>	Joint clinics between specialties <sup>**</sup>
Allergy	12	27	12	>10	>4			
Immunology	22	33	20	2	5	15	11	16
Dermatology		101	17	67	3	46	20	9
ENT	47	50				13		11
Occupational allergy		3						
Respiratory medicine	42	42	10	32	0	4	4	0

\* Self-reported provision of general allergy services covering the breadth of conditions in National Specialist Services definitions set 17 for allergy.  
† Self-reported provision of an allergy clinic focused on a very limited range of allergic disease, eg rhinitis, anaesthetic allergy.  
‡ Self-reported presence of a multidisciplinary team consisting of specialist nurse/dieticians/GP clinical assistants or other healthcare workers.  
§ Self-reported participation in regular educational or allergy/immunology service network meetings.  
\*\* Two or more specialties conducting a joint clinic at the same time in the same place focusing on an aspect of allergic disease (usually subspecialty).

Table 2 England and Wales: consultants/sites providing paediatric services

Main speciality	Number of hospital sites	Number of consultants	Number of sites with unselected allergy clinics as per NSSDS for allergy*	Consultants with subspecialty clinics†	Number of centres coding as allergy 317	Networked with others‡	Multi-disciplinary working‡	Joint clinics between specialities**
Paediatric allergists	12	20††	16	>7				
Immunology	7	7	7	2	1	7		
Dermatology		104						
ENT	41	50						
Respiratory medicine	3	3	3	0	0	3	3	0

\* Self-reported provision of general allergy services covering the breadth of conditions in National Specialist Services definitions set 17 for allergy.  
† Self-reported provision of an allergy clinic focused on a very limited range of allergic disease, eg rhinitis, anaesthetic allergy.  
‡ Self-reported presence of a multidisciplinary team consisting of specialist nurse/dietitians/GP clinical assistants or other healthcare workers.  
‡ Self-reported participation in regular educational or allergy/immunology service network meetings.  
\*\* Two or more specialities conducting a joint clinic at the same time in the same place focusing on an aspect of allergic disease (usually subspecialty).  
†† 10/20 paediatric allergists are in London; 16/20 spend >80% of working time on allergy.

These networks varied in their stage of development, size, and the time since they were instigated. Some have either established, or are working towards, guidelines on patient pathways within secondary care and guidance for primary care, shared education, research, audit and quality manuals. Most involve adult immunologists and allergists, or are paediatrician-led; some have widened their network to include other specialties and healthcare disciplines, including nursing and dietetics (eg TRIAC).

The BSACI identified initiatives in existing centres and networks, at the Royal National Throat, Nose and Ear Hospital; Imperial College London Healthcare NHS Trust; Guy's and St Thomas' Hospital; and allergy services in Devon and Cornwall.

## Immunotherapy

Although sales figures are difficult to interpret, the two major manufacturers of immunotherapeutic products did not report significant increases in people using subcutaneous immunotherapy (SCIT). There was, however, some evidence that sublingual immunotherapies (SLIT) are now being used. There are now an estimated 2,000 patients on each treatment modality annually, compared with very few on sublingual therapy in 2007. PCTs are still unwilling to fund immunotherapy. There are also wide variations in access to this treatment; children at specialist centres have better access than those seen elsewhere.

## Contracting for services

Foundation trusts, acute trusts, SHAs in England, and trusts and LHBs in Wales were contacted to ascertain the local provision of allergy services. A total of 39% of trusts in England and Wales responded; 23% provide in-house allergy services (mostly very limited) and 16% reported access to a referral service elsewhere. However, only 7% of PCTs in England and 33% of LHBs in Wales responded. Few trusts, PCTs or SHAs seemed to be clear about what a specialist allergy service should comprise, and few recognised how limited their provision actually is. Many centres with known allergy specialists provided no reply at all.

## Coding of service activity

Data from the company Dr Foster do not identify many known centres with large allergy workloads, and demonstrate that few clinics appear to be coding for allergy activity (missing large services in Plymouth, Bristol, Sheffield, Newcastle and Manchester). All datasets are likely to be erroneous, incomplete and potentially misleading, without triangulation between multiple data sources. In most, but not all, major allergist-led centres, allergy-coded activity seems to be collected (Guy's, Cambridge, Imperial, Royal Free, Leicester, Liverpool and Southampton).

## Conclusions

- ▶ There is little evidence that specialist services have substantially increased, and no evidence of increased resources available to them. A wide gap between need and provision thus remains.
- ▶ There is no evidence of a substantial increase in allergy specialists to provide leadership, but clear evidence of a desire to incorporate them when available. There

has been a small increase in consultant allergists, more in paediatric allergy than adult services, but more are needed, with a better geographical spread across England and Wales.

- ▶ There is evidence that some networks and centres have taken local initiatives to meet partially the recommendations of the HoL report, particularly with regard to networking and protocols. These should be shared.
- ▶ A significant number of clinicians, across multiple specialties in England and Wales, professed an interest in management of allergies and dedicate some time to allergy:
  - Most subspecialty clinics are run by clinicians who do not have allergy as their primary focus.
  - Coding information on activity is highly inaccurate outside major allergy centres, and would benefit from national benchmarking.
- ▶ There is clearly room for enhanced networking of all consultants working in allergy, and for improved coding:
  - Subspecialty clinics should participate in networks led by an allergy specialist; most declared an interest being involved in such a managed network and clustering of services.
  - We would encourage local and national networking as an obvious step to facilitate effective use of existing resources and improvement in quality to meet agreed national standards of care.
- ▶ A variety of sources of information on activity and services do not correspond:
  - Triangulation of databases from the British Society for Immunology (BSI), BSACI, our survey and the responses from trusts and PCTs reveal a lack of validated information, with incomplete and inconsistent data.
  - The absence of consistent and accurate data from different sources makes us question the accuracy of other data sources used for NHS planning.
- ▶ There appear to be serious deficiencies in commissioners' knowledge of:
  - the allergy needs of their local population
  - what an allergy service should provide
  - whether this is provided locally.
- ▶ Better patient involvement may improve these deficits.

### 3 Evidence of progress against key recommendations

#### Allergy centres

**Recommendation 10.1** We recommend that at least one allergy centre, led by a full-time allergy specialist, should be established in each strategic health authority. These centres would act as clusters of expertise of those with an interest in allergy, and should each contain a chest physician, dermatologist, ENT specialist, clinical immunologist, gastroenterologist, occupational health practitioner and paediatrician. Specialist nurses and dieticians trained in allergy would also be core team members.

#### *Evidence from the DH and the NWSHA pilot*

The DH has appointed the NWSHA as the lead strategic health authority for allergy, and they are piloting a novel approach to delivering allergy care. The NWSHA pilot reported many laudable aims. There was also considerable evidence of effective and energetic support from the North West commissioning team, who had prioritised allergy in the top nine works programmes of the North West Strategic Commissioning Group.

The project builds on a 2003 framework, which suggested three centres, but was unfunded. Its main objectives include:

- ▶ service reconfiguration
- ▶ aspirations to working smarter and improving capacity
- ▶ building on existing expertise
- ▶ identifying service gaps
- ▶ implementing better demand management
- ▶ developing outreach nurses and GPs with a special interest (GPswSi)
- ▶ development of outcome measures.

The NWSHA public engagement initiative showed a number of things:

- ▶ 72% of patients want to be seen by a specialist.
- ▶ >50% want that service to be local.
- ▶ Workload has almost doubled since 2005, to over 6,000 referrals.
- ▶ The emphasis was on ensuring appropriate use of limited resources.

- ▶ The aim was to provide integrated, equitable, high-quality, clinically effective allergy and clinical immunology services for children and adults across the NWSHA.
- ▶ There was an aspiration to ensure that the right patient gets the right treatment delivered by the right clinical team at the right place and at the right cost, with patient involvement.

Their vision for the regional service is a 'virtual allergy centre':

- ▶ Specialist-led centres would act as 'hubs', leading the managed clinical network.
- ▶ Allergy centres would be linked, forming the a 'virtual allergy centre'.
- ▶ Consultants working within a virtual network refer patients to colleagues with expertise in relevant areas.
- ▶ Common audit and standard operating procedures would be developed to link services together.
- ▶ To date, efforts have concentrated on the stabilisation of specialist allergy services for more complex patients.

Plans exist to increase the skills base, capability and capacity in primary and secondary care (but these may come unstuck due to lack of PCT support, and appointment of suitable candidates to key posts).

### *Care closer to home*

Equity and access to services closer to home should be improved. The proposals build on specialist clinical allergy in existing centres:

- ▶ South Manchester: respiratory
- ▶ Liverpool: immunotherapy
- ▶ Preston: ENT
- ▶ Central Manchester: anaesthetic allergy
- ▶ Salford: dermatology.

### *Leadership*

The NWSHA pilot should be overseen by a strategy board chaired by a PCT chief executive. It will meet from Jan/Feb 2010 on a bimonthly basis, with current 'working groups' evolving into 'implementation groups'. However, this has not yet begun.

### *Progress*

The main progress reported so far included:

- ▶ over £1 million of additional 'pump priming' investment from PCTs in the North West in 2 years, to support service improvement
- ▶ clinical evaluation study commenced (the DH funded £80,000)

- ▶ designation of tier 2b paediatric allergy centres (early 2010)
- ▶ dedicated project support (the DH funded £120,000 over 2 years)
- ▶ engagement of a PCT chief executive lead.

However, there remain substantial obstacles to progress, as noted below.

### *Aspirations*

Aspirations for the future report include:

- ▶ network priorities for 2010 of education, training and promotion of referral pathways managed service provision between the different centres
- ▶ the education of physicians, nurses and general practitioners (2010 onwards)
- ▶ improved links with local PCTs and local hospitals (2010 onwards)
- ▶ working with different disciplines and professions (2010)
- ▶ developing and reinforcing regional patient pathways and engaging the public in their development (2010 onwards)
- ▶ developing and testing locally agreed tariffs for evaluation (2010/11 and 2011/12)
- ▶ developing standard operating procedures and protocols (2010/11)
- ▶ making the best use of skills, money, equipment and accommodation
- ▶ developing quality assurance processes (from 2010).

### *Obstacles*

Several substantial obstacles to progress were identified:

- ▶ competition with other PCT 'must-dos'
- ▶ absence of allergy in Quality and Outcomes Framework (QOF) and primary care regulation – ie Care Quality Commission drivers are absent
- ▶ lack of available workforce/funding
- ▶ no benchmark for comparison (poor quality data)
- ▶ lack of outcome measures
- ▶ limited or no additional funding from 2010/11
- ▶ locally agreed tariff yet to be developed – a major uncontrolled risk
- ▶ development of management plans, guidance for primary care, effective cross-boundary referral mechanisms, community pharmacist protocols, consensus quality standards, regional patient pathways
- ▶ enhanced dietetic services
- ▶ enhanced very specialised services for the region

- ▶ quality assurance of allergy testing – especially with near patient testing – possible outreach role for nurse specialists
- ▶ failure to use GPswSI through lack of PCT support
- ▶ resourcing of increased education for supporting primary care
- ▶ lack of competency assessments and training frameworks.

### *Specialist paediatric allergy services in the North West*

The North West vision of paediatric allergy is ‘specialist-directed’ networking and training of primary, secondary and tertiary healthcare workers to provide efficient and effective service for patients close to home. As much as £410,000 of enhanced service needs had been identified, with one extra specialist allergist for each centre, two extra nurses, between two and four paediatricians with an interest, a part-time dietician, and administrative support.

### *Challenges for the paediatric service*

Funding for two specialist nurses and administrative staff (2010–11) has not yet been secured. A further challenge is provided by the fact that development of consensus information and guidelines has been agreed by all tiers of the network and is based on the latest evidence.

### *Occupational health*

At this stage, no formal occupational allergy practitioner service has been included.

### *Staffing*

Locally funded appointments have been made as follows:

- ▶ a full-time (adult) consultant allergist at the University Hospital of South Manchester NHS Foundation Trust (UHSM)
- ▶ full-time paediatric appointments in Manchester and Liverpool
- ▶ an additional adult immunologist in Salford.

This amounts to significantly fewer than the estimated need of 12 appointments based on the assessment of some of the professional and patient societies.

Since the whole project is dependent on local sources of funding, and the majority of allergy care is to be provided closer to home or in primary care (in compliance with general NHS policy), it is very worrying that clinicians in the North West reported that:

- ▶ ‘We have not been able to engage the North West PCTs at all.’
- ▶ ‘Virtually no PCTs came to the engagement event that the NWSCT put together about a year into the process.’
- ▶ Of the four PCTs asked to underpin the overheads associated with hospital-funded outreach nurse care positions, one declined, one eventually decided they couldn’t risk supporting it, and for a third there is ‘tentative agreement’. The fourth ‘is waiting to see what happens’.

- ▶ ‘We have someone (a GPwSI) in training’, ‘but have not found a PCT that will host him’. ‘His own PCT is not interested in him extending his role there’.

There is also concern about the long-term sustainability about all these arrangements, even if the obvious initial barriers are overcome.

#### *Evidence from professional groups and medical royal colleges*

- ▶ The North West pilot service reconfiguration is not yet fully worked through. Concerns were expressed about ongoing silo working and reluctance to integrate services fully.
- ▶ There was evidence that many of the initial differences between professional groups had been resolved and there was evidence of a common purpose.
- ▶ Resistance to change may make it difficult for the pilot to be replicated in other regions.
- ▶ Their solution may not work for all regions, even if successful.
- ▶ There was evidence of networking initiatives across the country (see Chapter 2) but little evidence of integration or sharing of initiatives.

The BSACI reported some success in expanding services in London, and aspirational developments in the South West. It restated its commitment to the development of at least one allergist-led allergy centre staffed by consultants in adult and paediatric allergy in every region. It reported that existing allergy centres need to be strengthened, especially where academic centres were operating on charitable and research grant funding.

#### *Evidence from patient groups*

- ▶ Patient involvement was slow and relatively late in instigation, but is now underway.
- ▶ Patient-led evaluation is not established across most of the UK.
- ▶ Lack of initial involvement has now been rectified, to the benefit of both parties.
- ▶ It was felt that the North West pilot model may not work for all regions.
- ▶ Concerns were expressed that the model differs from that proposed by the National Allergy Strategy Group (NASG), which has been supported by the patient groups.

The Anaphylaxis Campaign (AC) reported that the number of sites offering allergy clinics is slightly higher than the 94 identified to the HoL Committee by the BSACI. An allergy centre (as envisaged by the report) has not been established in each of the 10 SHAs, or in the three Welsh Health Authorities. The AC believed that many patients who are looked after by consultants from other specialities may be missing out on accurate diagnosis, important management and ongoing advice and care.

The BSACI, Allergy UK (AUK), the Allergy Alliance (AA) and the AC emphasised that:

- ▶ Patients had reported many complaints about existing services, from lack of knowledge to a lack of all round care and/or management.

- ▶ Patients want access to specialist-led centres, correct and accurate diagnosis, the provision of ongoing management of conditions and training for other physicians.
- ▶ Patients felt that having a specialist centre would ultimately improve patients' lives and save the NHS money.
- ▶ It remains unclear how best to collect patient experiences; electronic means should be developed.
- ▶ Patient-related outcomes measuring (PROMS) and long-term outcomes and follow up are needed.
- ▶ It was essential to present the patient perspective to PCTs, especially where there was a debate about who should be responsible for ongoing care and management.

The NASG viewed the North West pilot as a small response to a large problem, and reported that, in their view:

- ▶ Leadership from a consultant with wide experience and expertise in allergy was essential.
- ▶ An adequate number of adult and paediatric allergists were needed to develop a centre. Staff and services need time to develop. The NASG believe that the North West pilot will need six adult and six paediatric consultants to operate efficiently.
- ▶ There is a serious lack of funding. No central funding for the clinical services has been provided, and developments rely on local funding. Thus, sustainability is a concern.
- ▶ The lack of 'up-front' funding, combined with times of financial restraint, means that development will inevitably be difficult and slow.
- ▶ There must be a holistic approach to the patient and family.
- ▶ There should be an integrated care network – patients want high-level care in their local community, with a clear transition pathway for young people to follow as they transfer from paediatric to adult services.
- ▶ The NASG believe that monitoring and evaluation are essential if the pilot is to be of use in developing similar networks elsewhere, but that it is too early to evaluate the centre.
- ▶ The project has the potential to develop a better understanding of the fundamentals of a successful allergy service. The NASG will continue to work with the NWSHA via the NWSCT to help develop a service which can best serve patients locally, and eventually, to be evaluated effectively. The NASG believe there needs to be a long term approach to the development of a centre that can grow and be sustained for the future.

The Skin Care Campaign (SCC) reported that it was:

- ▶ not aware of many improvements at all in service provision since the publication of the HoL report, and have been disappointed in the laborious development in the North West, which would undoubtedly have benefited from appropriate funding from the DH and the appointment of consultant allergists

- ▶ concerned about the lack of integration and recognition for services already provided by dermatologists throughout the country
- ▶ clear about the need for the full and equitable inclusion of patients, patient organisations and allergy charities in the development of reports, guidelines and service developments.

### **Conclusions**

**The model that the HoL committee originally conceived was a ‘cluster’ of services. In the HoL report, the term ‘centre’ was used to represent such a clustering of services to bring together people with an interest in allergy for the benefit of patient services. The latest report from the DH supports that approach. Paediatric services must be considered integral to effective allergy service provision.**

**A single pilot site has been initiated but is in the early stages:**

- ▶ **Governance and evaluation structures are still in evolution, but could be improved.**
- ▶ **We recommend that a clinical leader is empowered by the network to bring about the necessary change to allergy services in the North West. A PCT CEO has been appointed as a champion, but meetings have yet to start, and a designated professional leader across the North West is urgently required.**

**The planned service only meets some of the recommendations of the HoL report, but remains to be tested in practice, and does not meet the original expectations of a centre staffed and led by multiple consultant specialists in allergy. Many of the reasons for this relate to factors outside the control of the North West project. Patient groups and some professionals fear it will not meet their expectations:**

- ▶ **Inequities in access to service were identified but not all were easily rectified, particularly in the north of the network, in Preston and Lancashire.**
- ▶ **There are difficulties in developing or accessing reliable NHS data on allergy, and there are no current outcome measures in place – these are urgently needed.**
- ▶ **Initiatives, protocols, guidelines and resources in the North West should be shared with other networks (and vice versa) to make best use of existing expertise and avoid duplication of effort.**

**While there was much commendable work from specialist commissioning teams and trusts, there was evidence of a lack of support from PCTs, with no PCT yet to commit to support, and several apparently having declined:**

- ▶ **Patient involvement in service design and PCT interaction should be strengthened.**
- ▶ **A shared vision, a commitment to cooperation, and good working relations between managers and clinicians, trusts and PCTs is essential.**

**We also note that:**

- ▶ **Attention and funding should be directed to parts of the country where services are less than adequate.**
  - ▶ **Existing large tertiary centres on a single site may not be the best way forward or the most cost-effective model for many parts of the country.**
  - ▶ **Shortage of specialist allergists may be a limiting factor in rapid centre development. Therefore local initiatives and networking – to work smarter and make best use of existing resources – are a potential way of laying the foundations for future development of specialist allergist-led hubs:**
    - **There is much unconnected activity which could be better utilised through networking. Professional isolation should be reduced through participation in networks.**
    - **Diagnostic laboratories need to be closely linked to clinical services and taken into account by commissioners when developing services.**
  - ▶ **What constitutes a ‘model of good practice’ for one region may not meet the needs of other regions or build on existing expertise; there is a need for clearly defined models of ‘good practice’ to promote standardisation of services and a need for an accreditation process.**
  - ▶ **Quality assurance (QA) for clinical allergy services and the role of accreditation need to be considered and developed to improve quality of care:**
    - **The QA mechanism should consider incorporating regular audit, protocols and guidelines, monitored training and competency, publicly available dashboards with regard to service quality.**
    - **The Joint Committee for Clinical Immunology and Allergy (JCIA) accreditation scheme should be supported and developed and must be open to all who practice allergy, including paediatric allergy. Services should be accredited where such a mechanism exists.**
  - ▶ **Service mapping must be improved, and this is best achieved by designating a lead SHA to amalgamate and triangulate all the existing disparate data sources.**
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**Recommendation 10.2** Each allergy centre should provide the diagnostic facilities necessary to investigate complex allergies, and should ensure that those who perform these tests have received accredited allergy training. Parallel clinics could avoid the need for multiple referrals and separate visits to hospital for those with multi-system allergic disease. Regular multidisciplinary team meetings will ensure that knowledge is shared and complex cases discussed. This places the needs of the patient first, allowing rapid accurate diagnosis that informs comprehensive patient management plans. The inclusion of paediatric allergists within allergy centres will ensure that children with allergic conditions are treated appropriately, and will enable a smooth transition from paediatric to adult allergy care.

#### *Evidence from the DH and the NWSHA pilot*

In the NWSHA pilot, multidisciplinary services comprising a number of specialists will develop agreed patient pathways to investigate and manage very specialised/complex allergy problems, building on existing specialist expertise. Examples include contact dermatitis, refractory chronic idiopathic urticaria, immunotherapy for multiple allergens, and investigation of anaesthetic and vaccine reactions. The University of Liverpool has also started a study to identify patients being treated for allergy by other specialties (not coded as ‘allergy’ but seen in respiratory, ENT and general paediatric clinics).

Tier 2b paediatric allergy centres will run regular joint allergy clinics with a general paediatrician with an interest in allergy and a visiting paediatric allergy specialist on a monthly basis. It is also envisaged that general paediatricians with an interest will visit the tertiary centre at regular intervals to develop and maintain their knowledge and skills in the management of more complex allergy, working to agreed protocols/standard operating procedures.

‘Rapid access asthma and allergy clinics’ have been running successfully for over 4 years, led by the advanced nurse practitioner at Alder Hey Children’s Hospital for children presenting to A&E with acute exacerbation of asthma or after an acute allergic reaction.

#### *Evidence from professional groups and medical royal colleges*

Little joint working for those with severe allergic disease is seen around the UK, although other disease groups, such as cancer, have shown benefit in patient outcomes from closer working and establishing one-stop points of consultation.

St Mary’s Hospital/Imperial College and Guy’s and St Thomas Trusts have regular transition clinics for young people with allergy, and Imperial College will appoint another consultant to lead this. Other centres are exploring the possibility of transition clinics.

The BSACI supports improved services for complex allergy, but feel that diagnostic facilities for complex allergic problems, eg drug allergy, have not improved.

The Royal College of Paediatrics and Child Health (RCPCH) has a working group now developing six care pathways for children with anaphylaxis, asthma/rhinitis, eczema, urticaria, venom/

drug/latex and food allergy, and has applied to the DH for funding to evaluate implementation of the first three of these.

### *Evidence from patient groups*

The AC is aware of no progress since the publication of the HoL report. The lack of integrated working between specialists leaves much of the UK devoid of access to allergy expertise, with a knock-on effect that there is no focus for GP education.

The SCC expects all services to put the needs of the patient first, and would expect a dermatologist to be a part of any allergy multidisciplinary team led by an expert consultant allergist with holistic expertise, supported by other specialties.

### **Conclusions**

- ▶ **All PCTs should commission and implement patient pathways for allergic disease from those specialists that encounter patients with allergy:**
    - **Such pathways should specify the lead clinician to ensure that interdisciplinary collaboration is maintained, and should include referral routes from primary care and from emergency departments.**
    - **It may be most efficient to adopt shared existing pathways for local or national use.**
  - ▶ **Achieving adequate numbers of allergy specialists in the short/medium term is unlikely, due to a shortage of training posts and lack of funding. The best use of existing expertise is required from the existing cadre of allergy specialists to develop leadership for all networks and services:**
    - **Many specialists are aspiring to plug the gap in the interim, and many are providing leadership in their own areas of expertise.**
    - **Flexible and creative thinking is needed to make best use of existing resources.**
    - **The majority of care is undertaken by those not specialising in allergy.**
    - **They need access to advice and support from specialists in allergic disease and its manifestations.**
  - ▶ **Patient groups, the BSACI and NASG all agree that a centre cannot be successful without leadership from allergy specialists.**
  - ▶ **Validated PROMs are needed if the success of any model of allergy service provision is to be assessed.**
  - ▶ **A common complaint from patients is that they want ‘holistic’ care, and feel that they cannot achieve this outside of a centre led by a specialist. All clinicians should be able to provide care that takes into the account the needs and aspirations of the patient and their demand for access to a high-quality efficient service, and services should be structured accordingly.**
-

**Recommendation 10.3** Once a diagnosis is obtained and a treatment plan developed at the allergy centre, the patient's disease can often be managed back in primary or general secondary care. However, patients with severe or complex allergic conditions may need long-term follow-up from specialists in the allergy centre. Allergen immunotherapy by injection should always be carried out by specialists within the allergy centre because of the risk of anaphylaxis.

#### *Evidence from the DH and the NWSHA pilot*

There is scope for care pathways to be developed in all SHAs, including distant referral for patients with complex allergic disease who should be investigated and managed in highly specialised centres (with follow-up nearer to home). Immunotherapy services are patchy in the North West region. The pilot is considering developments to increase the patients being treated for venom, pollen and drug desensitisation.

The NWSHA plan to work closely with a local GP who is in training to become the first GPwSI for allergy in the region. There was clear evidence that the lack of enthusiastic support from PCTs was a critical barrier to progress in the North West. Proposals for adult allergy services included:

- ▶ training and support for GPs who will continue to diagnose and treat the bulk of allergy using agreed map of medicine pathways that will detail when to refer on
- ▶ recommending training for community pharmacists in symptomatic treatment for conditions such as hay fever, and the encouragement of appropriate quality assurance measures for pharmacists undertaking point-of-care allergy testing
- ▶ more complex cases to be seen closer to home by specialist nurses and GPswSI.

#### *Evidence from professional groups and medical royal colleges*

There was evidence of some disagreement about the ability of primary care to deliver services. Some felt that 'there is almost no primary care allergic disease specialised expertise or service development in the UK'. Plans by the DH to expect allergic disease to be cared for in primary care are misguided and may be dangerous, as allergen challenge testing and injection immunotherapy should only be undertaken in places safely equipped to cope with severe anaphylaxis. The new 'biologicals' such as omalizumab are costly and require careful patient selection and detailed monitoring by specialist centres.

The Royal College of General Practitioners (RCGP) has recently appointed clinical champions for allergy who have the potential to identify and promote improvement in care and reflect the needs of primary care practitioners. The RCGP shares the current concerns about the problems with obtaining a thorough diagnostic assessment.

The BSACI believe that increased provision of allergen immunotherapy requires a marked increase in funding to boost the numbers of allergy trainees and centres able to administer such treatment. The provision of sublingual immunotherapy (SLIT) for severe uncontrolled hay fever

is constrained by the unwillingness of many PCTs to provide funding, although it appeared that SLIT was the only slow growth area in immunotherapy provision in the last few years, according to the manufacturers. In total, across more than 50 possible treatment centres, there appear to be only around 2,000 patients on SLIT, and 2,000 on subcutaneous immunotherapy (SCIT) in the UK at present.

A repeat BSACI postal survey of 149 UK GPs on allergy service provision revealed no improvement in GP perceptions of service provision between 2002 and 2009:

- ▶ 71% (95% CI 63–79%) of GPs rated overall NHS allergy care as poor.
- ▶ No improvement was seen in GPs' perceptions of the quality of allergy care provided in primary (p=0.33) and secondary care (p=0.97) or access to specialists (p=0.37) between 2002 and 2009.

### *GPs with a specialist interest and specialist nurses*

Numbers are very low. The RCGP has only been able to identify five GPs nationally who profess a specialist interest in allergy. The primary care group of the BSACI has been able to identify two additional GPs and four primary care nurses. In total, there are approximately 10 GPs and 5–10 nurses, some trained to diploma/masters level. Allergy has now been designated as a clinical priority area by the RCGP for the period 2010–12.

### *Evidence from patient groups*

*GPs know there is a huge unmet need. We often avoid looking for it as we do not have the time/other clinical priorities/lack of access to testing (skin prick testing particularly) in primary care/do not want to overload secondary care with mild-moderate cases. I also think a lot of GPs question the value of seeking allergy in atopic patients and generally are not aware of available medications/interventions.*

NASG GP Survey 2008

Patients are not able to access the services they need, and there is a widespread lack of confidence that primary care would be able to cope with most complex allergic disease.

A survey of GPs was carried out by the NASG during autumn 2008, and concluded that:

- ▶ 74 of 750 surveys were completed (10% response rate)
- ▶ 74% of responding GPs felt that milder allergy should be treated in primary care
- ▶ 74% felt that they did not have the necessary skills/knowledge to treat allergy
- ▶ 62% needed allergy education; 33% needed time and 17% needed more staffing
- ▶ only 39% attended a course on allergy but only 14% had received any allergy education in the last year
- ▶ 89% had referred patients to a secondary care specialist, but of the rest, 1/3 said that there was no allergy specialist, and 1/3 said that the specialist was too far away.

The SCC want involvement of expert patients in establishing gold standard pathways.

### Conclusions

- ▶ **Newer treatments have underlined the importance of this recommendation, which has not been adequately implemented, despite it probably being cost-neutral, if not cost-saving in the long-term.**
  - **Very poor perception of allergy education and service provision persists, with no evidence of improvement since the HoL report.**
  - **Expectations that primary care will be able to provide improved and enhanced allergy care are dependent on investment and engagement by PCTs.**
- ▶ **Evidence to date from the NWSHA pilot, where reconfiguration of secondary care and support from PCTs has not yet happened, suggests that better primary care allergy services will be difficult to achieve because of lack of PCT engagement.**
  - **There is evidence of local initiatives throughout the UK from individual services and networks, professional and patient groups, but these are not coordinated, quality assured or effectively networked nationally.**
- ▶ **We recommend a structured approach of ‘working smarter’ and sharing the learning/resource within and between networks to facilitate standardisation of care, quality assurance and accreditation.**
  - **Resourcing better education and support of outreach initiatives will be difficult with current levels of staffing and expertise unless very creative approaches to working practices are considered and allergy specialist input is improved.**
- ▶ **Electronic learning resources will be important in supporting implementation.**
  - **While there is evidence of slow uptake of SLIT, access is inequitable and funding remains a postcode lottery. There is no evidence of increased provision of SCIT nationally in the last 3 years.**

**Recommendation 10.4** New allergy centres should enhance and build on existing pockets of excellence to bring together existing clinics and specialists, and to develop and expand upon the services already offered. Where specialist allergist posts already exist, these allergists will be key to the new allergy centres, and should take the administrative lead with the appropriate time commitment. In other areas, new allergist posts should be established.

### *Evidence from the DH and the NWSHA pilot*

- ▶ The North West project is sufficiently large to require additional leadership from other specialties as well. There are currently simply not enough full-time allergists with the resource to do so.

- ▶ The North West will continue to provide highly specialised allergy services to build a cadre of practitioners with experience, and profess to be building on existing expertise.
- ▶ One full-time (adult) consultant allergist and one full-time paediatrician have been appointed and another paediatric specialist appointment is planned.
- ▶ Immunotherapy services are patchy in the North West. The pilot is considering service developments to increase the number of patients being treated.
- ▶ There remain no clear plans to improve access to services in the north of the region to a similar extent to the rest.
- ▶ The two paediatric allergy services, based in the tertiary children's services in the north west at Alder Hey Hospital and the Royal Manchester Children's Hospital, facilitate close liaison with other tertiary paediatric services such as dermatology, ENT, respiratory, gastroenterology, immunology and infectious diseases.
- ▶ Joint anaesthetic clinic activity with a national expert is incorporated in the project.
- ▶ Referral and gating protocols for dermatology were being developed.
- ▶ The Contact Dermatitis Investigation Unit in the North West is the largest in Europe, and has excellent links with Manchester University, occupational physicians and industry.

Respiratory medicine appeared to be the least integrated of the main specialties in the pilot, and it was felt that the problems of 'difficult asthma' are most often non-allergic in nature, so the question remained as to whether there was a need for a tertiary allergic asthma service.

#### *Evidence from professional groups and medical royal colleges*

The paediatric integration may provide a model for other parts of the UK. However, there is concern that the appointees will be detracted by general paediatric workload, as the allergy service is not being ring-fenced.

Despite a recommendation for an additional 20 paediatric and 20 adult allergist training posts by both the RCP (in 2003)<sup>5</sup> and the Commons Health Committee inquiry into allergy (in 2004),<sup>6</sup> there are only 12 allergy trainee posts (adult) in England, producing two new trained allergists each year. Many allergists are nearing retirement. The only other completely new posts established last year outside of the North West were: one consultant allergist at Nottingham; one clinical academic allergist at Guy's Hospital, one paediatric allergist at St Thomas'; and two at Imperial College (one academic, one NHS).

#### *Evidence from patient groups*

There is a great need for paediatric services accessible to families. Only five new single-life allergy training posts have been created by the DH since June 2007. Five immunology training posts were also created at the same time. The patient groups want to see more full-time paediatric allergy specialists appointed in the North West and elsewhere.

The SCC reported that it was vital that all new centres work in collaboration with established dermatology services and do not overlap/usurp any of their services, unless it can be proven that to do so would be in the best interests of patients.

### Conclusions

- ▶ **The paediatric developments in SHAs where services are already established need to be evaluated as potential models for service planning in other parts of the UK. However, different localities may require different models.**
- ▶ **Such evaluation should include an analysis of clinical efficacy and cost efficiency of the service, from the perspectives of service providers and users (patients and families).**
- ▶ **There is evidence of a current lack of allergy specialists/trainees to meet previously stated specialist staffing objectives. This is a substantial barrier to effective service planning in the short, medium and long terms.**
  - **In many areas of the country, leadership will have to come from a diverse range of specialists interested in allergy with the time, experience, ability, adequate continuing professional development (CPD) and inclination to take on this role in the first instance.**
- ▶ **There is a lack of consensus regarding the need for engagement with a multidisciplinary service in some specialties, especially respiratory medicine.**
- ▶ **There is evidence that the NWSHA are doing the best with what they have. This is necessary, rational and laudable.**
- ▶ **While it is an attractive concept, the putative benefits of ‘smarter working’ and better networking remain to be evaluated. Independent evaluation of the NWSHA and other models are urgently needed.**

**Recommendation 10.5** Allergy centres should be distributed nationwide, but it is not necessary for every allergy centre to provide every service. Some should become national reference centres for less common allergies, such as anaesthetic allergy. Patients therefore may need to travel a relatively long distance to a national reference centre for their condition, for accurate diagnosis and management planning. The patient should then be referred back to their local service and primary care practitioners for ongoing management.

### *Evidence from the DH and the NWSHA pilot*

The DH was still unclear as to what needs to be done on a supra-regional level, and who should decide which centre would lead on each specialist service.

### *Evidence from professional groups and medical royal colleges*

Service mapping at a national level is required to identify highly specialised services and to inform contracting. A lead SHA will be needed at national level to hold the information and advise other SHAs, who can then inform PCTs for contact negotiations.

Access to services is a key issue for the BSACI, who recognise that super-specialist allergy services will need to be concentrated in specialist centres. However, the care pathways for these services

will need to be clearly defined so that these services are accessible to all patients who need them. The problem with poor access has also been highlighted by the repeat GP survey conducted by the RCGP.<sup>4</sup>

### *Evidence from patient groups*

Patients want to know where optimal services are, to ensure that they have accurate diagnosis in a comprehensive and easily accessible form. The patient support groups could collate and hold such information for patients. They would want to work with a lead SHA to ensure that information is up-to-date. There is evidence that multiple sources of service listings are both overlapping and incomplete. Access to services is also a key issue for the AC, but they were not aware of further development regarding these centres for super-specialist allergy services since the publication of the report.

### **Conclusions**

- ▶ **Allergy centres, as defined by the HoL report, have not developed.**
  - ▶ **Multiple alternative solutions, with the potential to meet the HoL report recommendations partially, are apparently in place in various locations around the country but there is no linkage, standardisation or sharing of expertise. This should be promoted by extending participation in networks, preferably formalised and ultimately managed.**
    - **If these initiatives result in better service quality or standardisation at a local level, this will constitute a positive outcome.**
  - ▶ **The lack of comprehensive service mapping across the UK hinders the development of the most cost-effective ways of delivering services.**
    - **More allergy specialists will be essential to delivering this improvement.**
  - ▶ **The DH should appoint a new lead SHA to work with the lead patient group to ensure that accurate data collection on services is widely available.**
  - ▶ **Networked services should produce standardised evaluation data and share initiatives, models, protocols and pathways between themselves and with the North West pilot.**
  - ▶ **Accreditation and standardisation of care is essential to enable identification of the closest appropriate service meeting quality and governance standards.**
    - **The embryonic Joint Committee on Immunology and Allergy accreditation process for allergy services should be actively supported.**
-

**Recommendation 10.6** Collaboration between clinicians in primary, secondary and tertiary care is key to improving the diagnosis and management of people with allergic conditions. Once established, the allergy centre in each region should encourage and coordinate the training of local GPs and other healthcare workers in allergy. In a ‘hub and spokes’ model, the allergy centre, or ‘hub’, would act as a central point of expertise, with outreach clinical services, education and training provided to doctors and nurses in primary and secondary care (the ‘spokes’). In this way, knowledge regarding the diagnosis and management of allergic conditions would be disseminated throughout the region. In regions where there are GPswSI in allergy, they should also play a role in the ‘hub’ of the allergy centre.

#### *Evidence from the DH and the NWSHA pilot*

The North West pilot envisages the development of an integrated regional clinical allergy service, bringing together a group of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner to ensure the equitable provision of high-quality, clinically effective services in allergy across the region. The DH and NWSHA listed many aspirations for improved education and support for care closer to the patient in adult services, tier 2b paediatric service models, and hub-and-spokes operation. CPD for GPs and a GPwSI is planned in Manchester.

Plans were reported to develop primary–secondary care interface posts in PCTs, but all of these will fail without PCT support. There is already evidence that the North West Specialised Commissioning Group and trust efforts are not being replicated or underpinned at PCT level.

#### *Evidence from professional groups and medical royal colleges*

There has been little development of allergy service clustering to form hubs and their associated spokes, which seems likely to be the most common near-future structure for allergy care and service organisation.

The BSACI is not in agreement with the proposed provision of pharmacists with special interest in allergy acting as clinicians, since they will not have received the relevant basic clinical training. The BSACI has set up a primary care group whose remit is to improve allergy care at this level, with translation of BSACI guidelines into a format for primary care staff use.<sup>7</sup> The primary care group is also developing competencies to support the development of the ‘GPwSI in allergy’ role that will be submitted to the RCGP and stakeholder consultation. The BSACI has recently raised funds from industry to provide educational meetings for primary care throughout the UK. They strongly support the inclusion of allergy indicators in the QOF to incentivise primary care teams to focus on allergy, and PCT commissioners to prioritise them in relation to local need. Engagement of generalist paediatricians with the BSACI has recently increased; an email-based paediatric allergy group now has 800 members.

Earlier this year, the RCGP submitted a proposal to NICE to develop an allergy indicator, aiming to catalyse service improvements in primary care-based allergy provision.

### *Evidence from patient groups*

With some notable exceptions, such as in Cambridge and London, the patient groups at a local level have been inadequately engaged by NHS managers.

The AC have no evidence to suggest that the number of GPswSI has increased since publication of the HoL report, and support the inclusion of allergy services in the QoF system. Studies demonstrate a worrying lack of confidence in GPs to diagnose allergic conditions, leading to delays in diagnosis, and lack referrals to specialist care. Strong leadership in the ‘hub’ will allow for better knowledge to cascade out to the ‘spokes’.

The SCC believes that GPswSI do not always enhance the care of patients, and that GPswSI-orientated structures can give rise to ‘de-skilling’ of other primary care services. The SCC has an expectation of a good level of allergy expertise in every practice, and support the introduction of allergy components into existing QoF structures.

*H is allergic to most nuts – he avoids all nuts. He has been hospitalised by two reactions. Each time the triage nurse and front line medics don't seem to know how serious the condition could become. Only after persistence and lost tempers do we get to see a doctor whose alarm bells ring and we get immediate treatment. This can be very worrying for parents and frightening for the child.*

S, Yorkshire

### **Conclusions**

- ▶ **Implementation of a hub-and-spoke model is a complex process requiring clear leadership, collaborative teamwork, and good pathways of communication across discipline boundaries. It also requires collaboration between different provider organisations, and these relationships need to be explicit in the commissioning of services.**
  - **Such leadership needs to come from a clinician working in, and committed to, allergy.**
  - **Wherever possible, this clinician should have undertaken NHS leadership training.**
  - **The clinical leader needs to be able to champion cost-effective change, working with management and with other clinicians to improve the quality of service to patients.**
- ▶ **A clear strategy for GP education and outreach support has yet to be developed for the North West, but is crucial for service delivery, whatever model is used. This requires PCT support.**
- ▶ **Networking, sharing of initiatives and collaboration between patient groups, professional societies and networks are to be encouraged, and the professional societies may have a valuable role in facilitating this.**
  - **E-learning and document-sharing initiatives should be considered.**
- ▶ **Difficulties in engaging GPs to focus on allergy are evident in the absence of drivers such as NICE, QoF or PCT service level agreements (SLAs).**
  - **Inclusion of allergy-relevant targets in QoF structures is strongly recommended.**

**Recommendation 10.7** The allergy centre should act as a lead in providing public information and advice. Specialists at the centre should work in collaboration with allergy charities, schools and local businesses to provide education and training courses for allergy patients, their families, school staff and employers, in how to prevent and treat allergic conditions. Feedback between patient groups and allergy centres would enable the allergy centres to assess whether they were providing the necessary services, and would ensure that the advice offered by patient groups was accurate and updated in the light of rapidly changing scientific evidence.

#### *Evidence from the DH and the NWSHA pilot*

The NWSHA pilot has plans to improve advice, information and education. However, it is early days, and there are concerns about how this will be funded or resourced from secondary care.

#### *Evidence from professional groups and medical royal colleges*

There is a range of tools available for PROMs. There is a danger that some tools, although useful in research in allergy, are too complicated to administer in clinical services. The RCGP would like the National Institute for Health Research (NIHR) to fund development of PROMs for use in allergy care.

The BSACI is encouraging collaboration between allergy centres and patient groups. Imperial College and Southampton both have oversubscribed allergy MSc courses.

#### *Evidence from patient groups*

There is a very serious shortfall in accurate information available to patients. In several areas of the UK, patient groups have come together to form a local coalition of interests (eg AUK, AC, the Latex Allergy Support Group (LASG) and so on). These collaborative groups of patients are a potentially rich resource for patient input.

The AC provides workshops and support groups across the country, and would welcome closer collaboration with allergy centres. The AC also provides newsletters and patient information/membership leaflets to known allergy centres. Local volunteer support group networks could provide an 'expert patient' in each SHA region, as well as offering advice and education. For many, it is the only way for them to get even basic information following their initial diagnosis (if not seen in specialist centres providing information). The AC has run 'Allergywise' training courses for state school nurses in every PCT across the country. Private and independent schools will also be able to access online training from 2010. This service is wholly funded by the AC through donations, with no DH funding.

The SCC highlighted that many charities and patient support groups have well established information and possess the skills to provide appropriate advice; they should lead on this in collaboration with all stakeholders.

**Conclusions**

- ▶ **Patient groups can do more to ensure that there is a local coalition of allergy interests in each SHA, and to ensure that the members of the coalition actively seek out patient views on local services and have a mechanism to feed their findings back to the local allergy champion or PCTs.**
  - ▶ **Clinical services in many areas do not have established links with their local patient groups. These can be a valuable resource to constructive initiatives, especially in support of other patients, and should be sought out.**
  - ▶ **Some existing services do this on a local basis, but to varying extents.**
  - ▶ **Close collaboration and shared working should assist in developing patient information and educational initiatives. These are fostered by meetings (eg annual patient open days), which can be organised at a local level by the patient groups themselves.**
  - ▶ **Courses in allergy should include practical experience.**
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**Recommendation 10.8** We recommend that the DH should establish a lead strategic health authority, preferably not in the south of England, which would work with its primary care trusts to develop the first allergy centre. A full cost analysis should be integral to this to assess the efficacy of diagnosing and managing allergy using the 'hub-and-spokes' model. Improved education of clinicians in allergy, with an accurate diagnosis recorded on the Systematised Nomenclature of Medicine (SNOMED) system, should assist a thorough cost analysis to be carried out. The lessons learnt from the pilot allergy centre should then be used to inform the development of further allergy centres in other regions.

***Evidence from the DH and the NWSHA pilot***

Implementation is dependent upon PCT resources in the North West being allocated to it, but it competes with other priority areas in a context of increasing fiscal restraint, and the emerging impact of Health Resource Group (HRG4) payment-by-results tariffs. The pilot is exploring opportunities for tariff-based funding of the services, requiring the development of new allergy tariff bands. It is also exploring the means for funding outreach training by specialists who would otherwise be generating income by treating patients. Initially, the network plans to engage in audit and patient-recorded outcome assessment to determine the effectiveness of the model of care for patients with acute allergy in secondary and tertiary services, and to provide a regional view of trends in referral patterns.

***Evidence from professional groups and medical royal colleges***

The NHS computerised clinical record has been a major distraction during the past few years. SNOMED-coded data are collected in some regions, but not collated, so it is not effectively used to inform service development or contracting.<sup>8</sup> There is concern that tariffs for allergy services

will be too imprecise, and the NHS budgetary system too short-term to resource the needs of a national service adequately. They may not be sophisticated enough to allow innovations that may have an ‘invest-to-save’ element as services modernise and evolve to become more cost-effective in the long run.

The BSACI (and the AC) would welcome involvement, but there remain concerns around its development and the sustainability of the pilot. The NWSHA has a major task in developing a new allergy service, and allergy specialists need to be appointed to develop local expertise. They suggest that this role may be more appropriately provided by the National Specialist Commissioning Advisory Group (NSCAG).

### *Evidence from patient groups*

Patients have not been engaged in the development of outcome measures to date.

### **Conclusions**

- ▶ **The recommendation has been implemented in part by the NWSHA pilot, but the outcome is not certain, and there are concerns that the model will not be suitable for other SHAs, even if successful.**
  - **The committee agrees that the pilot is to evaluate a single model that may provide lessons and outputs (pathways, protocols, guidance, audit etc) which could be adaptable for use by other centres and by other models of service.**
  - **The final evaluation of change in the North West should be nationally reported and made widely available across the NHS.**
  - **Centres with established services should share their experience with developing services in the UK.**
- ▶ **National leadership in the form of a lead SHA or NSCAG is essential for effective and coordinated progress in comparative cost evaluation or data collection for all models.**
- ▶ **SNOMED classification and recording systems must be adopted nationally.**

**Recommendation 10.9** Once established, allergy centres in different regions should have a contractual obligation to share the resources they develop, such as standard operating procedures, clinical guidelines and patient information. The lead strategic health authority should ensure that there are national reference centres for rarer allergic conditions, such as some occupational disorders or adverse drug reactions.

### *Evidence from the DH and the NWSHA pilot*

Each trust providing specialist allergy services in the North West pilot has agreed to develop standard operating procedures and clinical guidelines across the region. These will be shared once they have been tested, but delivery timetables are unclear.

### *Evidence from professional groups and royal colleges*

No SHA has been appointed to take a lead role in allergy services nationally. Without this, more sophisticated models of cost-effective service provision are not being developed and there is no national reference point for meaningful comparison of different models of provision. NICE is planning to develop guidelines for some aspects of allergy service provision, but these will not replace the need for sharing of protocols.

The BSACI sees no evidence of progress. The role of the DH has yet to be clarified with regard to this proposed centralisation.

### *Evidence from patient groups*

There is no evidence of a national strategy to share resources and guidelines. The AC helpline receives numerous calls throughout the year from individuals reporting rarer allergic reactions, including exercise–food syndromes, occupational and drug allergies. Often, callers cannot get expert assessment as their GPs do not know where to refer.

### **Conclusions**

- ▶ **Everyone agrees that sharing protocols and guidelines is a good idea, but there is little evidence of this in practice.**
    - **Once developed, an allergy centre should have a contractual obligation to share resources.**
    - **Bidirectional sharing of information to and from the pilot, between patient groups and professional groups and between all parties, is encouraged.**
  - ▶ **While it is essential that information is shared, it is also vital that advice and training is evidence-based and quality-assured. There are no mechanisms for this in place, but consensus should underpin audit and accreditation processes to be developed.**
  - ▶ **A national system for service accreditation should be developed and then form part of the Care Quality Commission inspection processes.**
  - ▶ **A new lead SHA to oversee networking and data collection should be designated rapidly. All contracts for allergy services could then require that services provide their operating procedures and guidelines to the lead SHA.**
    - **A consensus group comes together to make examples of best practice available through the medical royal colleges or other sources.**
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**Recommendation 10.10** The lead allergist in each allergy centre should be responsible for maintaining a patient database to support clinical research within their region. The Office for Strategic Coordination of Health Research (OSCHR) and the Translational Medicine Funding Board should work with the lead strategic health authority to support clinical research in the allergy centres, and to coordinate national research projects. The establishment of allergy centres would provide the clinical environment to undertake future clinical evaluations of immunotherapy and complementary therapies.

#### *Evidence from the DH and the NWSHA pilot*

The NWSHA pilot has not as yet undertaken any research projects.

#### *Evidence from professional groups and medical royal colleges*

The failure of the DH to designate a lead SHA has hindered national collaboration. The absence of specialist allergy services in much of the UK is a major barrier to facilitating research.

#### *Evidence from patient groups*

Patients want to be involved in developing novel approaches to allergy.

*Once we got to see a dermatologist and a dietician, our lives changed overnight. We have a fantastic medical team now. It was such a fight in the first place.* LS, Maidstone

*We have no specialist assigned to us and when I reach my wits end I pay £300 a time to see a 'quite' good paediatrician with good knowledge of allergy, but he does not specialise in anaphylaxis.* KG, Devon

*The NHS allergy services that are available have very long waiting lists, because there are so few centres. As a result, it is difficult to obtain help when needed. When one does eventually see an allergy professional, the appointments are short, basic, and the treatment (if any) inadequate. My experience (and that of a school friend) was that appointments tended to be about monitoring rather than dealing with allergies.* J, aged 15

*I am allergic to grass and tree pollens. However, the desensitisation programmes for these allergies are not available on the NHS. If they were, there would be a more than 90% chance of eliminating the hay fever/rhinitis, leading not only to a better quality of life, but also the reduction in the need for medical intervention (not just for the hay fever but also the resultant asthma), saving more money for the NHS in the longer term.* Name supplied

*Those with severe allergies have to deal with potentially life-threatening situations 24 hours a day. When can we expect to see improved expert provision, particularly in the more isolated areas of the country?* C, aged 13

*I feel really upset because I have so many allergies to dairy, soya, eggs, nuts, fish, wheat and latex. I can't eat food that I would like to try, I feel left out in birthday parties, I feel that I am the only one with so many allergies and I think why me? I wish that there could be more doctors so that they can find a cure so I could get better and be like everyone else.* Y, aged 9

## Professional education

**Recommendation 10.11** It is vital that the Health and Safety Executive (HSE) works with the Department of Health to ensure that medical practitioners are adequately educated in the diagnosis and treatment of occupational allergic disorders. We support the work of the Group of Occupational Respiratory Disease Specialists convened by the HSE, which has developed a standard of care document for the diagnosis of occupational asthma, and recommend that the HSE should work with stakeholders to produce a similar document for occupational allergic skin disease.

### *Evidence from the DH*

The HSE part-funded the Health and Safety Laboratory (HSL) to develop a GP occupational asthma e-training programme based on the British Occupational Health Research Foundation (BOHRF) guidelines/standard of care document.

Development of a document for occupational allergic skin disease is underway. BOHRF has developed updated evidence-based guidelines for the identification, prevention and management of occupational contact dermatitis and urticaria and occupational asthma.<sup>9</sup> These were published in March 2010. HSE is providing funding in kind, by providing the scientific secretarial role.

### *Evidence from professional groups and medical royal colleges*

Understanding and managing occupational health issues requires a set of skills that are complementary to those used in 'normal' clinical practice:

- ▶ Almost all specialist referral occupational allergy provision is outside the NHS, and obtaining appropriate referral can therefore be difficult. Most is initiated through the employee's GP. This is inefficient – a system of direct specialist access would be better.
- ▶ Lack of provision of occupational allergy expertise in the North West pilot remains an issue.
- ▶ The HSE provided limited funding (not yet based on full economic costing) for the continuation of data collection by The Health and Occupation Reporting network (THOR):
  - for occupational allergy, until the end of 2010
  - for respiratory physicians until the end of 2011.
- ▶ The university team managing THOR has formed an EU network to develop a pan-European approach to monitor trends, and is seeking EU funding.
- ▶ In 2008, the BOHRF granted funding for the development of a systematic evidence review on occupational skin diseases and asthma, expected to be delivered in 2010.
- ▶ The LASG and the BSACI Standards of Care Committee is developing a guideline on latex allergy with the British Association of Dermatologists (BAD).

*Evidence from patient groups*

The SCC wants expert patient representatives to be involved as stakeholders with HSE and OH clinicians. Although the development of the Standard of Care document on occupational skin disease is welcomed, awareness of its development is poor and patchy.

The AA reported that new occupational health risks are arising. Following the change to nitrile/vinyl gloves to prevent latex sensitisation in healthcare settings, latex gloves are being sold from the back of vans into small scale catering businesses.

**Conclusions**

- ▶ **Occupational allergy provision with expertise in allergy is very poor.**
- ▶ **HSE funding appears uncertain for future sustainability of reporting and monitoring of occupational disorders.**

**Recommendation 10.12** The development of NICE clinical guidelines for the diagnosis and management of allergic conditions is no substitute for improving the training of those in primary care. We recommend that the medical royal colleges should work together to ensure that the training undergraduate medical students receive enables them to recognise the role of allergy in disease processes, and to refer patients appropriately. It is imperative that general practitioners develop their allergy knowledge through continuing professional development and as part of their membership of the Royal College of General Practitioners.

*Evidence from the DH*

The DH agrees on the importance of such training. However, they pointed out that others (the GMC and medical schools) were responsible for undergraduate and postgraduate medical training, nursing and pharmacist training. It is not possible to be prescriptive about specific training and development needs for GPs.

*Evidence from professional groups and medical royal colleges*

There is very little formalised allergy education for GPs, and no national curriculum in GP training in allergy. The RCGP has established an allergy working group empowered to spearhead appropriate training as part of accreditation in general practice.

The BSACI noted that the training in allergy received by medical students is extremely limited. It is essential that medical students are taught some allergy. The BSACI believe that, until there are consultant allergists in all teaching hospitals, this will not occur. A pilot study of GP/allergy clinic interaction is underway at the Royal National Throat Nose and Ear Hospital.

The BSACI Primary Care Group recently led a successful application to establish allergy as a clinical priority by the RCGP in 2010–12. The group will continue to work closely with the RCGP's 'Clinical Allergy Champions' to push for improvements in allergy services. The World

Allergy Organization has published guidelines for undergraduate training in allergy, which could be used as a template for the GMC in reviewing undergraduate curricula. The RCGP reported that approaches to assessing whether such training is being delivered adequately have been developed, and their use is encouraged.<sup>10</sup>

### *Evidence from patient groups*

The SCC feels that the medical royal colleges must include the Royal College of Nursing (RCN) and Royal Pharmaceutical Society (RPS), in order to ensure that all clinicians who could contribute to the patient pathway are trained properly.

### **Conclusions**

- ▶ **The challenge of improving primary care knowledge and expertise in allergic diseases is substantial. Such education should be commissioned as part of service level agreements.**
  - ▶ **There is widespread concern about the lack of allergy teaching and exposure in the undergraduate medical curriculum.**
  - ▶ **Local experts from all disciplines should be encouraged to teach general and subspecialty allergy to undergraduates and postgraduates in medicine and related professions.**
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**Recommendation 10.13** The medical royal colleges, the postgraduate deans, the Postgraduate Medical Education and Training Board, and the British Society for Allergy and Clinical Immunology should also work together to develop generic quality-assured clinical postgraduate courses in allergy. These should be for doctors in both primary and secondary care, and for nurses and others, particularly those wishing to become an accredited specialist in allergy.

### *Evidence from the DH*

The DH reported that this was the responsibility of other agencies.

### *Evidence from professional groups and medical royal colleges*

Accreditation standards and quality assurance mechanisms have yet to be developed for any professional group. The Allergy UK accredited pharmacist screening initiative has a distance learning training package, and is developing quality assurance procedures. Accredited DipHE/BSc level allergy modules are available via Education for Health.

### *Evidence from patient groups*

They are not aware of any progress having been made towards implementation.

Patients are not concerned with the training route that a specialist has taken. They are very concerned to ensure that the clinician involved in diagnosing their allergy and developing a

management plan is competent and up-to-date in allergic disease, and is willing to seek advice from other healthcare professionals as required, in the patient's best interests. The SCC want medical royal colleges and professional societies to include the RCN and RPS, to ensure that everyone who could contribute to the patient pathway are trained properly, as it is not just doctors who provide clinical support to people with allergies.

*I keep asking for allergy testing through my GP and get fobbed off, get told that I know best what I'm allergic to and a referral is more for nut allergies etc. I get allergies all year round and want more help. I'm sick of taking antihistamines all the time.* MD, Cheshire

*We were told on two separate occasions by two GPs at our local health centre that it was impossible for our daughter to be allergic to peanuts. Two specialists confirmed our fears later that year.* K, Leicestershire

*I am a GP. I find the demand for 'allergy specialists' greater than the supply. However, I feel the Anaphylaxis Campaign has more to offer following initial diagnosis than services within the NHS.* GP, London

*The GP said he had no training in allergies and a slow reintroduction to nut traces may be the way to go, not strict avoidance. This horrifies me.* Mrs M, Darlington

*After 28 years of suffering with eczema and various topical treatments I finally saw a locum GP who suggested I had allergy tests. They showed that I was severely allergic to sodium laureth sulphate – as soon as I started using a non-SLS shampoo my eczema dramatically improved.* 30-year-old woman

## Research and product development

**Recommendation 10.14** Although high-quality research into cellular and molecular mechanisms of allergy is advancing, the factors contributing to allergy development and the 'allergy epidemic' are poorly understood. It is imperative that further research should focus on the environmental factors, such as early allergen exposure, which may contribute to the inception, prevention or exacerbation, of allergic disorders. Long-term cohort studies are a vital part of this research, and interventional studies are key to verifying the role which these factors may play. We look to the development of the OSCHR to improve the coordination and funding for these types of projects.

### *Evidence from the DH*

The DH reported that the Medical Research Council (MRC), the DH through the National Institute for Health Research (NIHR), and the Food Standards Agency (FSA) are actively supporting research in these areas, and the level of that investment is increasing through the following channels:

- ▶ King's College London and Imperial College London host researchers for the Asthma UK Centre in Allergic Mechanisms of Asthma.

- ▶ The Medical Research Council–Health Protection Agency (MRC–HPA) Centre for Environment and Health (King’s College London and Imperial College) researches the effects of air pollution and health.
- ▶ The Wessex severe asthma cohort hosted by University of Southampton was also funded (£680,000).
- ▶ The NIHR Biomedical Research Centre at the Guy’s and St Thomas’ NHS Trust/ University College London, funded for £4.7 million over 5 years, is undertaking research on asthma and allergy, including immunotherapy, new therapeutic strategies, and the early origins of disease.
- ▶ The Imperial College Healthcare NHS Trust/Imperial College Biomedical Research Centre is being funded to undertake research to identify novel targets for the prevention and treatment of childhood allergy and asthma.

#### *Evidence from patient groups*

The SCC states that all healthcare interventions should be as holistic as possible, and evidence should be developed to show effective psychosocial approaches.

#### **Conclusions**

- ▶ **The FSA has funded food allergy research over the last 20 years and has a continuing programme.**
- ▶ **A limited amount of research is currently funded, mostly on asthma.**
- ▶ **Much of the research funding identified is generic and not targeted at the questions or areas of investigation suggested by the HoL report.**
- ▶ **There is probably some indirect allergy funding through collaborations within the EU and with US organisations such as the Immune Tolerance Network (ITN).**

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**Recommendation 10.15** We are concerned that the knowledge gained from cellular and molecular research is not being translated into clinical practice. We therefore regard allergy research directly related to healthcare to be an area of unmet need that requires greater priority. The Translational Medicine Funding Board must ensure that allergy research is applied to develop novel individualised treatments. The cost of a central disease registry may be too high to warrant investment. Therefore, a comprehensive patient database within each allergy centre will be key to epidemiological and other studies, and is best maintained by ownership at a local level.

#### *Evidence from the DH*

The Translational Medicine Board was established by OSCHR in July 2007.

The MRC continues to support high-quality research into the underlying causes of allergic responses and underpinning research into the development of novel approaches to combating these conditions, spending £5.9 million in 2007–8.

Under the Experimental Medicine Initiative, funds were committed to furthering our understanding of immunotherapy in allergic dermatitis and therapies for asthma, totalling £735,000. In addition, work within the MRC centres previously mentioned is targeted towards translation of findings into patient benefit, including asthma and food allergy.

The MRC is also working with the FSA to explore opportunities for synergy between basic immunology and food allergy research.

The NIHR Health Technology Assessment programme has commissioned two studies, with a combined value of £2 million, on asthma treatments:

- ▶ a randomised controlled trial of intravenous or nebulised magnesium sulphate or standard therapy for acute severe asthma
- ▶ an assessment of alternative approaches to the management of asthma in school-age children on therapy.

### Conclusions

- ▶ **There is little evidence of progress against the recommendation, as much research funding is indirect and thus difficult to identify and collate.**
- ▶ **We were unable to identify or locate any new disease registers.**

**Recommendation 10.16** Immunotherapy is a valuable resource in the prophylactic treatment of patients with life-threatening allergies, or whose allergic disease does not respond to other medication. Although initially expensive, immunotherapy can prevent a symptomatic allergic response for many years, and may prevent the development of additional allergic conditions, so its wider use could potentially result in significant long-term savings for the NHS. We recommend that NICE should conduct a full cost–benefit analysis of the potential health, social and economic value of immunotherapy treatment.

### *Evidence from the DH*

Following the HoL recommendation, NICE considered whether it would be possible to develop guidance on immunotherapy, but concluded that the topic was too broad. NICE held a workshop with allergy specialists in February 2009 to generate possible topics resulting in referral of the two short clinical guidelines that relate to ‘the diagnosis and assessment of food allergy in children’ and ‘the initial assessment and decision to refer following emergency treatment for an anaphylactic episode’. A number of other allergy-related topics relating to areas such as allergic rhinitis, drug allergy and wasp/bee immunotherapy are in the topic selection process.

### *Evidence from professional groups and medical royal colleges*

Oral immunotherapy is available in the UK, but it is rarely prescribed, with slightly more than 2,000 patients on treatment in the UK at present and static numbers of SCIT use.

Desensitisation to other precipitants of severe or chronic and debilitating allergic reactions is inadequately considered in routine clinical care, probably through a lack of services at a national level. In addition, the history of adverse reactions experienced during injection immunotherapy in the past (1970s) has left a legacy of reluctance to employ desensitisation in routine practice (though it should be noted that orally-administered desensitising preparations do not have the same risk profile as injectable allergen preparations).

#### *Evidence from patient groups*

*Research is required on the emotional development of children with allergies – families are left to cope with the emotional fallout of living with such anxiety. It affects all members of the family including siblings who potentially lose a lot of freedom too.* S, Herts

#### **Conclusions**

- ▶ **There appear to be some early signs of progress on evaluating immunotherapy. We hope that it will be subject to NICE appraisal.**
  - ▶ **Access to immunotherapy appears to remain suboptimal, with inadequate access to new types of oral immunotherapy.**
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## Food

**Recommendation 10.17** It is imperative that environmental health officers, trading standards officers and catering workers are adequately and comprehensively trained in practical allergen management. We welcome the development of a training programme by the Food Standards Agency (FSA) and recommend that the FSA should work with other training providers to produce consistent practical training courses of a high standard.

#### *Evidence from the DH*

In September 2009, the FSA launched the ‘Safer food, better business’ teaching resources for use in catering colleges.

In 2007, the FSA launched a series of food allergy training workshops for local authority enforcement officers across the UK on advising food businesses on allergen management. In 2008, the Agency added an e-learning module.<sup>11</sup> In addition, the FSA has run a series of incident prevention workshops across England. It has also published a best practice guide on food allergen management for foods that are not pre-packed, to enable catering establishments to provide accurate information about food allergens in their products.

#### *Evidence from professional groups and medical royal colleges*

Considerable progress occurred prior to publication of the HoL report, largely through cooperation between the FSA and the AC. Posters at the BSACI annual meeting in July 2009 demonstrated a continuing dangerous lack of knowledge in temporary restaurant employees.

*Evidence from patient groups*

The AC, AA and SCC felt that many patient support groups have established resources for this and should work with the HSE.

The AC reported that the FSA supported their development of an allergen control standard for food manufacturers and a further standard for the catering industry. The AC feels that enforcement officers need a much firmer lead from the FSA. The FSA should require local authorities to provide coordinated feedback on the results of allergen sampling, allergy incidents that they have investigated, and the action that they are taking against businesses.

AA reported that current studies on quality of life provide insight into the deficiencies in food allergen avoidance which still exist. While some officers are taking a proactive approach, others are far less confident and reluctant to act proactively or even to respond to fatal or potentially fatal incidents. There is a serious risk, particularly when local authority funding is increasingly tight, that initiatives to protect allergic people by controlling allergens, surveillance activities and training will be reduced or abandoned. Most deaths and 'near misses' involve use of an unexpected or unrecognised ingredient. The UK must ensure that current draft EU regulations on the provision of food information enable all consumers always to find out what is in all food on sale, and ensure that check systems are in place to support this in every food business.

**Conclusions**

- ▶ **There has been some progress on this recommendation, with commendable involvement of the patient societies, but enforcement of good practice is variable.**
- ▶ **There are concerns that there may be a reduction in vigilance if food standards inspections are fewer and less stringent.**

**Recommendation 10.18** It is imperative that work is carried out to investigate whether peanut consumption or avoidance in early life significantly affects a child's risk of developing peanut allergy. We therefore support the work of the Learning Early About Peanut allergy (LEAP) study. We are very concerned that Department of Health dietary advice regarding peanut consumption for pregnant women and infants is based upon evidence that was reported 9 years ago. Recent evidence suggests that this advice has not succeeded in reducing the prevalence of peanut allergy, and may indeed be counterproductive. We recommend that this advice should be withdrawn immediately, pending a comprehensive review by the Food Standards Agency and the Committee on Toxicity of Chemicals in Food, Consumer Products and the Environment.

*Evidence from the DH*

The Committee on Toxicity (COT) considered the review of evidence published since the previous Government advice was issued in 1998 and issued its statement in December 2008.<sup>12</sup> The FSA and the DH revised the advice to take account of the new COT conclusions in August

2009.<sup>13,14</sup> This amended advice is incorporated into *The Pregnancy Book*<sup>15</sup> and *Birth to Five*<sup>16</sup> in England that were re-launched in August 2009.

### ***Peanuts***

*If you would like to eat peanuts or foods containing peanuts (such as peanut butter) during pregnancy, you can choose to do so as part of a healthy balanced diet, unless you are allergic to them or your health professional advises you not to.* The Pregnancy Book

*You may have heard that some women have, in the past, chosen not to eat peanuts when they were pregnant. This is because the government previously advised women that they may wish to avoid eating peanuts during pregnancy if there was a history of allergy in their child's immediate family (such as asthma, eczema, hay fever, food allergy or other types of allergy). But this advice has now been changed because the latest research has shown that there is no clear evidence to say if eating or not eating peanuts during pregnancy affects the chances of your baby developing a peanut allergy.* The Pregnancy Book

### ***Nuts***

*As long as there is no history of food or other allergies in your family, you can give your baby peanuts, as long as they are crushed or ground into peanut butter.* Birth to Five

*You may have heard that previous advice was to avoid giving your child peanuts before the age of 3 years – this advice has now changed, based on the latest research, and you only need to avoid giving peanuts before 6 months of age.* Birth to Five

*If your child already has a known allergy, such as a diagnosed eczema or a diagnosed food allergy, or if there is a history of allergy in your child's immediate family (if parents, brothers or sisters have an allergy such as asthma, eczema, hayfever, or other types of allergy) then your child has a higher risk of developing peanut allergy (see page 15). In these cases you should talk to your GP, health visitor or medical allergy specialist before you give peanuts or peanut-containing foods to your child for the first time.<sup>11</sup>*

### ***Evidence from professional groups and medical royal colleges***

This advice has now been withdrawn (August 2009). The BSACI believes further research is required so that there is evidence on which to base advice. The RCGP has been involved with propagating this new advice.

### ***Evidence from patient groups***

The AC will work with the DH to get any new message across to the allergic population and relevant healthcare professionals such as midwives and health visitors, as expectant and new mothers seek allergy-related advice from these groups.

*My son, aged ten, has severe disabilities but the thing that prevents us from leading an ordinary life is his severe nut allergy. We have recently stayed in four-star and five-star hotels in the UK and neither would cater adequately for him. We had to resort to eating out at McDonald's, where staff were able to produce ingredient lists.* M, Lancashire

*Stress! Constant worry and forward planning essential, therefore turning down invitations. It would be great to get a takeaway sometimes.* CW, Cambridge

### Conclusion

- ▶ **The 1998 advice on eating peanuts in pregnancy has been modified.**

## Schoolchildren

**Recommendation 10.19** We recommend that the Department for Children, Schools and Families (DCSF) should review the clinical care that hay fever sufferers receive at school, and should reassess the way in which they are supported throughout the examination season. The DCSF should also ensure that the provisions made by different schools are fair and consistent.

### Evidence from the DH

The Joint Council for Qualifications already advises exam boards that pupils who suffer from hay fever can be considered for special consideration when taking exams.

### Evidence from professional groups and royal colleges

The BSACI feels that services for hay fever must be improved, and that this requires more specialist allergy centres and more facilities and funding for pollen immunotherapy in children, to ensure that they can perform at their full potential, particularly in exams. The RCGP supports moves to non-sedating treatments. There are strong clinical, social and economic reasons to intervene early in the treatment of hay fever.

### Evidence from patient groups

The AC stated that evidence from our members suggests that provision is highly variable across the country. The SCC want same level of support provided to children with atopic eczema.

*Exams were particularly dreadful, very stressful and tiring. I always worry about disturbing others by sneezing and/or coughing.* RH, Cambridge

*I have had comments like 'I won't be asking your child to come for a play/birthday party because it is too much hassle feeding him'.* NS, Southampton

*My son is due to start nursery and I am petrified. Nurseries have very little if any understanding at all. I rang round infant schools in my area and am appalled to learn that they know nothing at all. In many cases they had to ask me for information and advice... without my care, my son is at risk, even with my best efforts I am concerned and scared.* L, Surrey

*My son cannot have a school dinner. They feel unable to take the risk as non-fresh produce has a nut allergy warning on it. This has been hard for a four-year-old to understand.* H, Manchester

### Conclusion

- ▶ **There is no evidence of any changes that are supportive of children with allergic disease during the exam season.**

## 4 Evidence of progress against further recommendations

### Monitoring allergy

**Recommendation 10.20** We recommend that the Department of Health should ensure the Systematised Nomenclature of Medicine (SNOMED) system is supported by appropriate training, to ensure its efficacy as a simple consistent classification system to record allergic disease, monitor its prevalence and inform the commissioning of allergy services.

#### *Evidence from the DH*

The training requirement to ensure the proper use of SNOMED Clinical Terms (CT) is related to the deployment of detailed care record systems by local service providers as part of the National Programme for IT. SNOMED CT is being built into these systems and training will be a local responsibility associated with their deployment.

#### **Conclusions**

- ▶ **Timelines are unclear, with variations in local implementation plans.**
  - ▶ **There is an essential requirement for better data coding, collection and analysis throughout the NHS.**
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**Recommendation 10.21** We welcome the involvement of the Health and Safety Executive in EU working groups to standardise the collection of data on occupational illness. The use of common standards in the diagnosis of occupational allergic conditions would allow international comparisons of disease incidence, and enable the evaluation of disease reduction strategies. We recommend that the Health and Safety Executive should fund The Health and Occupation Reporting network with the full economic cost of its surveillance programmes, and we urge the government to ensure support for this work in the future.

#### *Evidence from the DH*

The government's response of November 2007 continues to reflect the present situation. The Health and Safety Executive (HSE) is currently considering the future of all the extant schemes and the need to continue funding them beyond the current contracts.

### *Evidence from professional groups and medical royal colleges*

See responses to recommendation 10.11.

#### **Conclusions**

- ▶ **Occupational allergy provision is perhaps the most difficult service area to improve, as many occupational health services are outside the NHS, sited in employing organisations or the HSE.**
- 

**Recommendation 10.22** Information from children on sensitisation and symptoms is especially important and must be followed up to assess the progression of allergic diseases in order to predict workload. We recommend that future epidemiological studies measure not only the incidence of allergic symptoms, but also record the prevalence of confirmed allergic sensitisation.

### *Evidence from the DH*

The director general of research and development at the DH has written to research funders to draw their attention to the importance of recording the prevalence of allergy in epidemiological studies.

### *Evidence from patient groups*

In various other EU member states (France, Norway, Italy, Germany, Austria and Switzerland), there are now funded reporting networks to collect data on allergic reactions leading to anaphylaxis, together with follow-up clinical data and anonymised patient profiles.

The AC continues to work with immunologist Dr Richard Pumphrey to investigate fatal cases in the UK, to provide expert advice to HM coroners, and to offer support to families who have lost somebody to an allergic reaction. It is essential that this key surveillance is continued, funded and formalised, not only to inform health service provision but, more importantly, to ensure that there is improved evidence-based understanding of risk behaviour and better targeted patient guidance.

#### **Conclusion**

- ▶ **Further long-term epidemiological studies are essential to the nation's health and to service planning.**
-

## The air we breathe

**Recommendation 10.23** We recommend that the Department of Health should work with the Department for Communities and Local Government to support and encourage controlled trials involving multiple interventions, to examine the effect of ventilation, humidity and mite-reduction strategies on allergy development and control. As chemicals used in the construction industry may play a role in triggering symptoms in some allergic patients, further evaluation of their role is also required in order to inform procurement policies.

### *Evidence from the DH and the NWSHA pilot*

The DH is working with the Department for Communities and Local Government on proposed building regulations to ensure that adequate purpose-provided ventilation and air quality are maintained, to guard against mould growth in more airtight, energy-efficient buildings. The Committee on the Medical Effects of Air Pollutants has begun work on a report on the possible role of air pollutants as a cause of asthma. The MRC–HPA Centre for Environment and Health is researching the effects of air pollution and health.

### *Evidence from professional groups and medical royal colleges*

The BSACI notes that measures to reduce the need for heating homes by increasing insulation may decrease ventilation and increase mould and house dust mite populations.

### **Conclusion**

- ▶ **Very little effective action on implementation has taken place, and much more effort is needed.**
- 

**Recommendation 10.24** As climate change and air pollution may significantly impact upon the development of allergic disease, we support the thrust of the recommendations in the report, *Air quality and climate change: a UK perspective*.<sup>17</sup> We recommend that, when developing policies for industry, transport or housing, the government should take account of the interlinkages between air quality, climate change and human health.

### *Evidence from the DH*

The DH is working closely with both the Department for Environment Food and Rural Affairs (DEFRA) and Department of Energy and Climate Change (DECC) on air quality and climate change issues to implement recommendations in the report *Air quality and climate change: a UK perspective*. The HPA has established a small group of experts to work on the effects of ozone and heatwaves on health. The medical consequences of flooding have also been recognised by the HPA as a priority area. Work on the post-flooding indoor environment has begun. This is, in part,

focused on mould growth in damp conditions. The DH has also part-funded the publication of the World Health Organization (WHO) guidelines for indoor air quality, dampness and mould.

#### *Evidence from professional groups and medical royal colleges*

The BSACI recommends greater cooperation between the Meteorological Office and pollen counting centres to provide timely advice regarding fungal spore levels, which have been associated with near-fatal and fatal asthma in July and August, with asthma prevalence rates expected to increase due to climate change.

#### *Evidence from patient groups*

*June and July are 'no go' times for me: no weddings, picnics, walks or social events!*

Mrs J, Wales

#### **Conclusion**

- ▶ **Legislation to decrease passive smoking and address climate change has raised awareness of air quality, but the effect of particulate matter on allergy remains under-researched.**

## Schoolchildren

**Recommendation 10.25** We support the use of individual care plans for children with medical needs, as described in the government guidance *Managing medicines in schools and early years settings*. However, we are concerned that many teachers and support staff within schools are not appropriately educated in how to deal with allergic emergencies. We recommend that the Department for Children, Schools and Families should audit the level of allergy training these staff receive, and should take urgent remedial action to improve this training where required.

#### *Evidence from the DH*

The Child Health Strategy concludes that all children with long-term medical conditions and/or significant disabilities should have an individual care plan by 2010, to ensure that health professionals and teaching staff can anticipate, avoid and respond appropriately to events such as anaphylactic shock. Staff who manage or administer medicines should receive appropriate training and support from health professionals. 'Guidance on First Aid for Schools' would include allergic reactions. Schools must, on their employer's behalf, take reasonably practicable steps to ensure their pupils' health and safety.

#### *Evidence from professional groups and medical royal colleges*

The BSACI supports expert assessment and a management plan (produced by an allergy specialist with the parents and communicated to the school involved in the child's care) to reduce further reactions. Links between the allergy team and the community paediatric team should be

established to ensure training of school staff. They want guidance from the government to ensure that this occurs in all schools.

There are some local initiatives which have been highly successful and adopted by AC and AUK. Sharing of good practice will be important. Many networks and clinicians have existing written information and care plans.

In the Southampton University Hospitals, a Group for Asthma and Allergy Management and Education in Schools (GAMES) has been established, with training of school nurses to deliver training to school staff and education to the pupils. Its value has been evaluated in relation to asthma.

### *Evidence from patient groups*

The AC offered seminar-based training in allergy management for school nurses across the UK. The training programme is now available as e-learning, accredited by the RCN, offering two options. One tier meets professional needs and the other is aimed at the needs of parents, allergy sufferers and others who are interested. Published studies show that the risk of further reaction and death decreases if the patient has had expert assessment and participates in a management plan. Guidance from the government should ensure that schools adhere to this. Calls to the AC helpline suggest that treatment of allergic pupils is variable. Medical needs are reasonably well catered for, but management and avoidance strategies, and more detailed central guidance, are needed.

The SCC believes that a specific quality measure should be included in all Office for Standards in Education, Children's Services and Skills (OFSTED) assessments.

Allergy Action delivers training programmes for early years and infant schools, including the management of preventer and rescue medication, allergy risk assessment for both food and non-food risks, and practical guidance on supporting children with asthma and allergies across the full curriculum (including special trips and visits).

### **Conclusions**

- ▶ **Networks and centres should standardise, share, and quality-assure their support mechanisms for schools, and involve patients in their development.**
  - ▶ **Better DH and OFSTED guidance is required.**
  - ▶ **Adherence would be ensured if an OFSTED quality measure were introduced.**
  - ▶ **Support for voluntary sector initiatives should be considered as a cost-effective way of improving care.**
-

**Recommendation 10.26** We are concerned about the lack of clear guidance regarding the administration of auto-injectors to children with anaphylactic shock in the school environment, and recommend that the government should review the case for schools holding one or two generic auto-injectors.

#### *Evidence from the DH*

The DH does not plan to implement this, as adrenaline auto-injectors are a prescription item given on an individual basis by a specialist. DCSF guidance advises that schools should only accept prescription medicines clearly labelled and intended specifically for a named child, to prevent potential errors in use of generic devices.

#### *Evidence from professional groups and medical royal colleges*

The BSACI agrees with the Australian Society for Clinical Immunology and Allergy (ASCIA), which advocates an adrenaline auto-injector in first aid kits for use in any allergic reaction.

#### *Evidence from patient groups*

The AC supports this recommendation and summarised evidence from Norton *et al*<sup>18</sup> showing a ‘broadly positive response from parents and schools’ for generic adrenaline auto-injectors. At least two US states allow the use of generic adrenaline in schools.

*My school has no plan for managing children with food allergy. Where can I get training from and how can I get them to take it seriously?* AC helpline call

*Daughter with severe nut allergy – was excluded from play group for 2 weeks until they could investigate their insurance cover. No help from NHS in training staff so I demonstrated how to use the [adrenalin auto-injectors] to staff myself. Her pre-school would not take responsibility for any medicines so I left her there without any medicines and she was not able to eat anything when attending the session.* Mrs R, Canterbury

#### **Conclusion**

- ▶ **The provision of generic auto-injectors requires primary legislation and there is little likelihood of progress on this recommendation in the near future.**

## Workforce

**Recommendation 10.27** We welcome the educational work of the Health and Safety Executive to raise awareness and decrease the risk of occupational allergic disorders amongst employers and staff, and would like to see this work developed. Once allergy centres have been developed, we recommend that the HSE should liaise with the occupational allergy specialist in each centre to inform its policies and develop strategies to prevent occupational allergic disorders.

### *Evidence from the DH*

The HSE continues to engage with clinicians expert in the field of allergic occupational lung disease, both formally, through groups such as the Group of Respiratory Disease Specialists (GORDS), and informally.

### *Evidence from patient groups*

More needs to be done to educate the allergic population to ensure fewer reactions. There is little evidence of progress. The LASG would need to be involved in this area.

AA emphasised the importance of considering problems in occupations other than food handling and healthcare – aside from the risks from poor hygiene – due to complacency when wearing gloves, eg serving food, taking cash and offering change without washing hands. There is an increased opportunity for staff to be sensitised and for customers to receive food with traces of latex. Latex gloves are also widely used in childcare for nappy changing, by beauty therapists, hairdressers, mechanics and many other people in the workplace.

Much education and training is dependent on the voluntary sector and patient groups.

### **Conclusion**

- ▶ **There is no evidence of implementation outside food handling.**

**Recommendation 10.28** We are concerned that employees who are forced to leave work due to an occupational allergic disease can remain unemployed for long periods of time. We recommend that job centres should review the way they work with employers, to improve the way in which they can assist these workers to enter retraining schemes and find alternative employment.

### *Evidence from the DH*

Jobcentre Plus have been developing and improving the services that they provide to people with a health problem or disability, including those forced to leave employment due to an occupational allergic disease.

A consultation exercise has been undertaken and, from Autumn 2010, a new specialist disability programme – the Work Preparation and Job Introduction Scheme – will replace the existing WORKSTEP, with a single streamlined and flexible package of support tailored to individual needs. Closer links with Access to Work will also be developed.

Following concerns raised recently by the Sheffield Occupational Health Association, Jobcentre Plus will be considering whether there are any practical steps they could take to raise awareness of Access to Work amongst people claiming Industrial Injury Disablement Benefit (IIDB) to support them in returning to work. IIDB may be available to some people with more severe allergic reactions, such as occupational dermatitis.

#### *Evidence from patient groups*

*I am a medical student and can't stay 'scrubbed' up in theatre because I have to keep blowing my nose!*

LW

#### **Conclusion**

- ▶ **Steps towards implementation of recommendations have been impeded by rising national unemployment rates during the recession.**

## Information for consumers

**Recommendation 10.29** Vague defensive warnings on labels for consumers with food allergy can lead to dangerous confusion and an unnecessary restriction of choice. We recommend that the Food Standards Agency should ensure the needs of food allergic consumers are clearly recognised during the review of food labelling legislation being undertaken by the European Union.

#### *Evidence from the DH*

A proposal for an EU Regulation on Food Information was published in January 2008, and includes a new requirement for the provision of allergy information on foods sold unpackaged, including catering establishments. The FSA has already produced best practice guidance in 2006 to help businesses to improve their allergen management and advisory ('may contain') labelling. Evaluation of the effectiveness of this was published in 2009.<sup>19</sup>

The clinical sensitivity of individual allergic consumers is generally not determined, and can vary over time. Therefore, specifying the level of an allergenic ingredient in a food is unlikely to be of benefit to individual consumers in making choices. However, the FSA is driving forward international discussions on approaches to setting allergen management thresholds for use by the food industry in labelling possible cross-contamination. This includes joint-funding two international multi-stakeholder workshops on approaches to allergen risk assessment and tolerable levels of risk.

#### *Evidence from professional groups and medical royal colleges*

The BSACI and RCGP believe that defensive warnings on food labels are likely to lead to risk-taking behaviour, particularly among teenagers who are at risk of anaphylaxis.

### *Evidence from patient groups*

The AC stated that the FSA has issued firm and sensible guidance to food manufacturers and retailers on the use of defensive warning on food labels. The FSA has also grant-funded the AC Allergen Control Standard for food suppliers. Help for the industry does exist, but it is not being widely adopted. The FSA needs to take firm action to enforce adherence to current guidance. It is vital that the draft EU regulation on the provision of food information enables all consumers to find out the ingredients of food offered for sale, whether prepacked or non-prepacked, and the FSA must best represent the interests of allergic consumers.

Food ingredient information on packets is still illegible, printed in packet creases, in tiny fonts, in hard-to-read colours and on shiny surfaces. Such labelling has led to severe allergic reactions and one fatality. The AC demands that the FSA and local authority officers enforce the law as regulators that information is ‘clearly legible, easily visible and marked in a conspicuous place.’ There has been one recent prosecution for ‘selling unsafe food’ under food safety legislation (178/2002 EC) – a takeaway meal containing a peanut sold to a self-declared peanut allergic. Local authority officers are still not doing enough to protect allergic people from allergen risks in food outlets. Severe and costly reactions and fatal cases continue to occur, even when allergic people take steps to protect themselves.

*Shopping is very difficult for me, because of products being labelled so defensively, where ‘traces of nuts’ appears on almost everything, when this is not the case. Going out to eat also causes problems as staff are either over cautious or totally unaware of the risks involved. This makes me feel embarrassed and not able to join in properly with my friends. I would be so much happier if the general public and health professionals had more insight and accurate information on dealing with and treating allergies.*

J, aged 12

**Recommendation 10.30** As sensitivities to various allergens vary widely, we believe that setting standardised threshold levels for package labelling is potentially dangerous for consumers with allergies. Instead, we recommend that food labels should clearly specify the amount of each allergen listed within the European Union directive, if it is contained within the products, and we endorse the Food Standards Agency’s initiative to discourage vague defensive warnings.

### *Evidence from the DH*

See responses to recommendation 10.29.

### *Evidence from professional groups and medical royal colleges*

The BSACI thinks that this is neither necessary nor sensible, since the amount of allergen needed to produce anaphylaxis varies with individual and with circumstances. The presence of any allergen should be noted; the amount is irrelevant.

### *Evidence from patient groups*

The AC is not aware of any progress in taking this recommendation forward. The AC does not consider this recommendation helpful to consumers or realistic for the food industry.

### Conclusion

- ▶ **There was no evidence of better allergen labelling.**

**Recommendation 10.31** The phrases ‘hypoallergenic’ and ‘dermatologically tested’ are almost meaningless, as they only demonstrate a low potential for the products to be a topical irritant. We recommend that such products should warn those with a tendency to allergy that they may still get a marked reaction to such products.

### Evidence from the DH

The General Product Safety Regulations impose a duty to supply products that are safe in normal/reasonably foreseeable use, including providing appropriate warnings/instructions in the language of the market. Trading standards enforce the General Product Safety regulations, and will take action when they feel an absence of appropriate labelling or warnings renders a product unsafe.<sup>20</sup>

### Evidence from professional groups and medical royal colleges

The BSACI suggests that ‘hypoallergenic’ and ‘dermatologically tested’ terminology should be disallowed. There is no evidence of effective or active surveillance for breaches, and trading standards cannot act if the product is unsafe for a particular allergic consumer but safe for most of the population.

### Evidence from patient groups

The AC is concerned that ‘hypoallergenic’ and ‘dermatologically tested’ serve no purpose. The SCC prefers a total ban on the use of this ambiguous and potentially dangerous labelling.

*Labelling is unclear, inconsistent and over the top, and means I am unable to shop in many places, including Tesco. Please can a simpler and more sensible approach to labelling be enforced?*

H, 11 years old

### Conclusion

- ▶ **Misleading and potentially harmful labelling persists; there is little evidence that eradication of these labels is imminent.**

## Advice for people with allergies

**Recommendation 10.32** Many teenagers and young adults with food allergies sometimes take dangerously high risks when buying food. We therefore recommend that the Department of Health, working with the Food Standards Agency, charities and others, should explore novel ways to educate young people about allergy and the prevention of anaphylaxis.

### *Evidence from the DH*

The FSA is working with the DH to produce resources for food allergic consumers, to help them to make safe and informed food choices. In 2007, the FSA collaborated on the production of two short films for the Life Channel for use in GP surgeries, on food allergy and food intolerance.

The FSA worked to include food allergy within the National Curricula for schools across the UK, including resources for use by teachers, and with the National Governors' Association, in the production of the second edition of its *Food policy in schools – a strategic policy framework for governing bodies*, published in May 2007.<sup>21</sup> In 2008, the FSA produced chef cards, an online resource that can be filled in and printed by allergic consumers, to use when discussing their food allergy with caterers. The agency also published articles in 2008 in the print media, aimed at teenagers, to highlight the issue of food allergy and the information that is available from the agency to help food allergic people manage their food choices.

### *Evidence from professional groups and medical royal colleges*

The BSACI agrees that this is crucial.

### *Evidence from patient groups*

The SCC proposes that there would be benefit in including the Department for Children, Schools and Families (DCSF, formerly the Department for Education) and expert health educators in this work.

The AC agrees that this is crucial. The campaign is currently seeking to improve its communications with this group, and has developed web-based solutions, including an e-newsletter and Facebook participation. The AC also runs specific workshops for teenagers and their parents.

Calls to the AC helpline suggest that a time of particular anxiety for allergic youngsters and their parents is the transition from school to college and university, and the subsequent exposure of the allergic student to high risk situations through the ignorance of others. Both the allergic individuals, and those who come into regular contact with them, need to be educated.

AA report that more studies on living with food allergy are underway (within the Europrevall integrated project) at the universities of Derby, Southampton, Surrey and Edinburgh, among others. The FSA Allergy Branch works closely with the AC to establish ways to address these risks. AA does not have the same relationship with the DH.

### Conclusions

- ▶ **There is some evidence of implementation, but through reliance on patient groups and the voluntary sector.**
- ▶ **Involvement of the DCSF and expert health educators would enhance the quality of this work.**

**Recommendation 10.33** We recommend that the education of children about indoor air quality and its role in allergy development should be a priority for the interdepartmental steering group producing the ‘Children’s Environment and Health Strategy.’

### Evidence from the DH

The HPA was commissioned by the DH to develop recommendations for the UK to meet its commitments under Children’s Environment and Health Action Plan for Europe (CEHAPE) to protect children’s health. A Children’s Environment and Health Strategy for the UK was published on 24 March 2009. This national strategy recommends that local strategies are developed to protect and promote children’s health, including paying attention to respiratory health, and indoor and outdoor air pollution.

### Conclusion

- ▶ **Strategic evaluations are happening, but there is no evidence of actual education of children in this matter.**

**Recommendation 10.34** Allergy charities play an important role in providing public advice, but must continue to work together and with clinical services to avoid duplication of work, and ensure that consistent, evidence-based policies and public advice are provided.

### Evidence from the DH

The government recognises the important contribution of allergy charities. The DH has provided support through the Third Sector Investment Programme by awarding £51,000 to AUK for their project Alliance for Health in 2009–10.

### Evidence from professional groups and medical royal colleges

The BSACI and RCGP support this recommendation, and suggest that all patient charities should have well qualified clinical allergy advisors.

### Evidence from patient groups

The AC works closely with clinical advisors and internal experts to ensure that the most up-to-date, correct advice is given through its website, helpline and information literature. It would be

helpful if clinical advisors, who have access to research papers and studies, could systematically supply allergy charities with details of any new research and studies.

### **Conclusions**

- ▶ **There is evidence of desire on the part of the NWSHA pilot and patient groups to work more closely, but there are practical difficulties in achieving this.**
  - ▶ **There is substantial evidence that the patient groups have much to offer in terms of support for improved service redesign, innovative educational initiatives, and communication.**
  - ▶ **The committee is pleased to have catalysed a renewed engagement within the NWSHA project.**
  - ▶ **The committee is glad to see it has fostered the coming together of patient groups at local level across the UK, to provide a resource to healthcare providers for collaboration in local initiatives.**
  - ▶ **A list of patient representatives is being collated through the NASG.**
- 

**Recommendation 10.35** Pharmacists are often consulted by the general public about allergic conditions, and thus lift a significant burden from general practitioners. It is therefore essential that the advice offered regarding allergy is accurate, and should be given by trained pharmacists rather than unqualified assistants. We recommend that, as part of the implementation of the Pharmacists and Pharmacy Technicians Order 2007, adequate allergy education should be provided for all pharmacists, to ensure that they provide high quality advice to allergy sufferers.

### ***Evidence from the DH***

The DH was unable to provide much reassurance, as this matter is outside its remit.

The General Pharmaceutical Council was established by the Pharmacy Order 2010, which replaced the Pharmacists and Pharmacy Technicians Order 2007. The new order gives the new General Pharmaceutical Council the power to set standards in education and training. The standards will be the subject of consultation.

### ***Evidence from professional groups and medical royal colleges***

The BSACI view is that all allergy testing should be undertaken in a clinical setting and overseen by a member of the medical profession.

Negative specific IgE test results do not always rule out allergies. Thus, inappropriate interpretations of negative and positive specific IgE results performed in unskilled point-of-care testing (POCT) settings could lead to anaphylaxis as well as nutritional deficiencies in patients. There

was concern among many of the professional bodies that there was no validated evidence of effective training, quality assurance or governance of the process, neither for interpretive diagnostic skills or quality assurance of any near patient testing methods in use.

### *Evidence from patient groups*

Following the death of Katherine Baker in 1998, her family and the AC worked closely with the Royal Pharmaceutical Society of Great Britain on a 'Red Book' – guidance on managing a range of emergencies occurring when people walk into a chemist because their health is in danger. Recently, awareness of this guidance has waned and, in a survey, more than half of pharmacies questioned did not have both adult and child's dose injectable adrenaline available. The AC has evidence that pharmacists have been called upon to respond in some of the fatal and 'near-miss' cases reported. Pharmacists have also been called by HM Coroner to give evidence at inquests in cases of food allergy.

*The Anaphylaxis Society (sic) is our main source of information and support rather than the NHS.* Mr and Mrs C, Doncaster

*Without the help and support of the Anaphylaxis Campaign our lives would be much less healthy and we would have had many more hospital visits.* C, Milton Keynes

### **Conclusions**

- ▶ **There are considerable concerns, particularly from the professional organisations, about training, quality assurance and governance of these near-patient testing arrangements.**
  - ▶ **There is a lack of evidence of safety, efficacy and outcomes.**
  - ▶ **There was some evidence of potential initiatives to address the lack of quality assurance and CPD for the testing aspect of near-patient services (eg a POCT scheme using UK National External Quality Assessment Service for immunology, immunochemistry and allergy).**
  - ▶ **There is currently little clarity regarding the delivery of training and monitoring of skills, competencies or CPD for pharmacists and other professional groups delivering near-patient testing/advice on allergic conditions.**
-

## Evaluation of complementary techniques

**Recommendation 10.36** We recommend that robust research into the use of complementary diagnostic tests and treatments for allergy should examine the holistic needs of the patient, assessing not only the clinical improvement of allergy symptoms, but also analysing the impact of these methods upon patient well-being. Such trials should have clear hypotheses, validated outcome measures, risk–benefit and cost-effectiveness comparisons made with conventional treatments. Allergy centres will allow the collection of information about any indirect consequences of misdiagnoses or delayed treatment.

### *Evidence from the DH*

The government accepts that research into the effectiveness of complementary treatment should address the outcomes that the committee identifies. The Director General of Research and Development at the DH has written to research funders to draw their attention to the committee's recommendation.

The MRC would welcome applications from this area of research and would consider these for response mode funding should applications meet the required standards for competitiveness.

### *Evidence from professional groups and medical royal colleges*

The BSACI supports this recommendation. Some well-conducted studies have been published and show that some complementary diagnostic techniques give unreliable information and are ineffective in diagnosing true IgE-mediated allergy, yet many patients remain unaware of this and may receive inappropriate advice and possibly harmful diets.

### *Evidence from patient groups*

The AC supports this recommendation. The SCC report that, as many people with allergies are choosing to use more complementary therapies, high-quality research must be encouraged in this area.

### **Conclusion**

- ▶ **Professional and patient groups tend to have a different perspective on the necessity for further evaluation.**
  - ▶ **Caveat emptor ('buyer beware') remains an essential maxim.**
-

**Recommendation 10.37** We are concerned both that the results of allergy self-testing kits available to the public are being interpreted without the advice of appropriately trained healthcare personnel, and that the IgG food antibody test is being used to diagnose food intolerance in the absence of stringent scientific evidence. We recommend further research into the relevance of IgG antibodies in food intolerance, and with the establishment of more allergy centres, the necessary controlled clinical trials should be conducted. We urge general practitioners, pharmacists and charities not to endorse the use of these products until conclusive proof of their efficacy has been established.

### *Evidence from the DH*

The Medical Devices Regulations do not regulate the way in which a device is used, nor its efficacy. This is left to the individual clinician/service authorities to determine. The Medicines and Healthcare products Regulatory Agency (MHRA) is aware of only one over-the-counter allergy test kit available to the public. It has not received any adverse incidents with regard to problems in interpreting it. The EC In Vitro Diagnostic Device Directive (IVDD) aims to harmonise standards across Europe to create a single market. They do not regulate the service provider or advice to patients. Limiting the use of such kits to healthcare professionals would require separate national service legislation.

### *Evidence from professional groups and medical royal colleges*

The BSACI believes that there should be sufficient access to an appropriate level of NHS allergy services to ensure that these tests are not used as a default service by the public.

The Royal College of Pathologists and the BSI have considerable concerns about the lack of effective external quality assurance of point-of-care or laboratory use of unvalidated tests.

There is considerable misunderstanding in government, the professions and the public about the reliability and clinical utility of tests – all test results are essentially unreliable without proper interpretation. Allergy testing is an extreme example of this, with the results being essentially meaningless without interpretation in the specific clinical context. This cannot be done effectively without considerable training and up-to-date expertise. Minimal standards of ongoing CPD should be required to maintain competence.

Participation in meaningful, independent, third-party quality control and quality assurance is essential for all testing scenarios, but is rarely in place for POCT.

The MHRA underestimates the use of such testing because it only focuses on applications for IVDD-compliant tests. Self-declaration of compliance for in-house tests on the market before the introduction of the legislation minimises scrutiny, and the MHRA cannot receive complaints about clinical utility, despite the fact that it is the only really important function of the test device. The MHRA can be no safeguard in this matter.

To underline this point, although the MHRA is not aware of the use of any IgG allergy testing in the UK, this type of test appears to be available within the UK.

*Evidence from patient groups*

All agree that self testing is an inadequate substitute for access to expert NHS services.

**Conclusions**

- ▶ **The MHRA appears unaware of the full range of allergy/intolerance testing in use in the UK.**
  - ▶ **MHRA and IVDD compliance evaluations do not ascertain whether a test is clinically useful or effective – this is a major problem with current test evaluation.**
    - **This is a risk to patients which needs to be addressed.**
  - ▶ **We are concerned at the poor understanding of the quality assurance processes relevant to diagnostic test provision and clinical interpretation in many spheres, from the DH to the patient societies.**
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