



House of Commons  
Health Committee

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# **The Provision of Allergy Services**

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**Sixth Report of Session 2003–04**

*Volume I*





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Health Committee

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**Sixth Report of Session 2003–04**

***Volume I***

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### Contacts

All correspondence should be addressed to the Clerk of the Health Committee, House of Commons, 7 Millbank, London SW1P 3JA. The telephone number for general enquiries is 020 7219 6182. The Committee's email address is [healthcom@parliament.uk](mailto:healthcom@parliament.uk).

### Footnotes

In the footnotes of this Report, references to oral evidence are indicated by 'Q' followed by the question number. Written evidence is cited by reference to Volume II of this Report, in the form 'Ev' followed by the page number.

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## Summary

Allergies affect around 30% of the adult population and 40% of children. The prevalence, severity and complexity of allergy in the population is rapidly rising. Perhaps as many as one in 50 children in England are now allergic to nuts—almost a quarter of a million children. Anaphylaxis, which may be fatal, is now much more common.

We find serious problems exist in the current provision of allergy services. Those working in primary care lack the training, expertise and incentives to deliver services. We call for these deficiencies to be addressed. We recommend that a network of primary care allergy providers be created with a named lead for allergy in each Primary Care Trust. We ask for improved incentives for GPs to treat allergy and for better training. We recommend that a framework is developed to facilitate the introduction of allergy into the GPs with Special Interest programme, and for the Department of Health (the Department) to support this initiative. Without an adequate specialist service, primary healthcare professionals do not receive the necessary clinical training, nor are they supported when managing more complex cases within primary care. Further, they are not able to refer the most serious or complex allergy appropriately.

Many of the deficiencies in primary care are matched by weaknesses in secondary and tertiary care. Such secondary care for allergy as presently exists is largely performed by organ-based specialists, for example, dermatologists. There are only six full-time specialist allergy centres, with none at all north of Manchester or west of Bournemouth. The majority of funding for specialist services flows from academic sources rather than the NHS.

Current provision we describe as manifestly inequitable, and we endorse the proposal of the Royal College of Physicians that there should be a minimum of one specialist allergy centre in areas equivalent to each of the former NHS regions, serving populations of five to seven million, with a minimum staff of two adult and two paediatric allergy consultants (supported by paediatric nurse specialists); two full-time nurse specialists; and one half-time adult and one half-time paediatric dietician. While this specialist service is being developed we believe Strategic Health Authorities (SHAs) should co-ordinate provision to assess where unmet need is greatest. In the longer term we would like allergy to have a full specialist consultant workforce, as is the case in many other countries, and call for each major teaching hospital to have a consultant-led service. This is our key recommendation and will provide the specialist expertise and infrastructure, on which all other elements to develop a national allergy service within the NHS will depend.

We believe that the creation of a specialist allergy service nationwide will do much to improve the care of children with allergies, many of whom are being treated inappropriately in adult settings. Such a network, linked to a community paediatric team, will allow for better support for schools, but in the meantime we call for SHAs to ensure that community paediatricians liaise with major allergy centres for advice on management of children at risk in schools, and for schools and local education authorities to be guided by best practice protocols produced by Department for Education and Skills and the Anaphylaxis Campaign.

Much poor and even dangerous practice exists in the independent sector. We note that the remit of the Healthcare Commission currently extends only to those facilities providing medical treatment and call for it to be required to inspect organisations providing diagnostic services.

Dr Stephen Ladyman MP, the Minister with responsibility for allergy provision, disputed that there was clear evidence of unmet need. However, we find that the data on patient waiting times are flawed and call for the comprehensive introduction of the National Code to record allergy services. We also believe that the very absence of specialist services is contributing to the perception that there is not unmet need, as there can be no waiting lists for clinics that do not exist. Where specialist services become available they very soon come under considerable pressure even from the local population. Given the serious inequality of access to allergy specialist services we believe there would be merit in the National Specialist Commissioning Group treating the specialist allergy services as national services, eligible for specific NHS funding. We welcome the Minister's suggestion that he should ask the Chief Medical Officer to prepare an action plan to find ways of stimulating the commissioning of allergy services by PCTs, and we look forward to its publication, which we hope will take account of the conclusions of our report.

To provide allergy with a specialist workforce we recommend that training provision for adult allergy should be increased with an additional 10 posts in 2005 and a further 10 in 2006, with a similar number being provided for paediatric allergy. The Department will need to endorse and underwrite the creation of additional consultant posts for trainees to move into.

Finally, we call on the Department to issue a strategy document in response to our proposals and those contained in the Royal College of Physicians report *Allergy: the unmet need* (2003), to show that it takes seriously the growing problem of allergy, and to provide a catalyst for change.



# 1 Introduction

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1. Allergies affect around 30% of the adult population, and 40% of children, making these amongst the commonest diseases in England.<sup>1</sup> Approximately 15 million people in England now suffer from allergies, of whom 10 million will experience symptoms in the course of a year. Allergy in the population is rapidly escalating, especially in children. Until 1990 peanut allergy was rare. By 1996 the prevalence amongst children was one in 200. The figure may now be as high as one in 50—almost a quarter of a million children.<sup>2</sup> Whereas in 1979 only two cases of latex allergy had been recorded, now some 8% of healthcare staff suffer from this condition.<sup>3</sup> According to the Royal College of Physicians' (RCP's) working party on the provision of allergy services in the UK, "international comparisons show that the UK population has the highest prevalence of allergy in Europe and ranks among the highest in the world".<sup>4</sup>

2. Despite the high prevalence of allergy in the population, expert or specialist allergy treatment is very difficult to access within the NHS.<sup>5</sup> The great majority of GPs have received little allergy teaching as students and no extra postgraduate training. There is approximately one specialist consultant per two million of the population, as opposed to one per 100,000 for a mainstream specialty such as gastroenterology.<sup>6</sup> Specialist clinics are very few and are largely concentrated in the South East. Everywhere there is an enormous gap between the need for allergy services and their provision.

3. We announced our intention to hold this inquiry on 29 April 2004 with the following terms of reference:

*The Committee will inquire into the provision of care and treatment for allergies by the NHS and the independent sector.*

*In particular the Committee will examine:*

*Availability of allergy services (including issues such as geographical distribution, access times and patient choice) and specialist services for patients with severe allergies;*

*Priorities for improving services;*

*Governance and regulation of independent sector providers, and links between the NHS and the independent sector.*

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1 Royal College of Physicians, *Allergy: the unmet need—A blueprint for better patient care*, 2003, p7 [hereafter cited as 'Allergy: the unmet need']; Ev 110 (Dr Chris Corrigan)

2 Ev 125 (Dr Gideon Lack)

3 Ev 169 (Royal College of Physicians)

4 *Allergy: the unmet need*, p7

5 Ev 35–36 (British Society for Allergy and Clinical Immunology/National Allergy Strategy Group); Ev 53 (British Society for Allergy and Clinical Immunology)

6 *Allergy: the unmet need*, p7

*The scope of the inquiry will not extend to issues relating to clinical treatment of specific allergies and levels of incidence of allergies.*

4. On 17 June we took oral evidence from: Muriel Simmons, chief executive of the charity Allergy UK; David Reading, director of the Anaphylaxis Campaign; Dr Shuaib Nasser, consultant allergist, Addenbrooke's Hospital; Professor Stephen Holgate, Chair of the National Allergy Strategy Group (NASG); Professor Andrew Wardlaw, President of the British Society for Allergy and Clinical Immunology (BSACI); Professor John Warner, paediatric allergist, Southampton University; and Dr Lawrence Youlten, consultant allergist at The London Allergy Clinic. On 1 July we took evidence from Dr Stephen Ladyman, MP, Parliamentary Under-Secretary of State for Health and officials from the Department of Health (hereafter 'the Department').

5. In addition we received around 80 written memoranda from a variety of professional bodies, pressure groups, charities and clinicians. We also received well over 300 memoranda from individuals, either sufferers of allergy or parents/carers of people with allergy. These indicated some of the problems faced by those affected by allergy, and we append an analysis of these submissions to this report. We are most grateful to all who provided written or oral evidence.

6. In the course of the inquiry we undertook a visit to the Children's Asthma & Allergy Centre, Llandough Hospital, Cardiff. Dr Mazin Alfaham, a general paediatrician with an interest in allergy, and his team, described their experiences of running a paediatric allergy clinic and shared with us their views on the prevalence of allergy and the provision of allergy services. We are most grateful to them for finding the time to see us.

7. Our specialist adviser in this inquiry was Dr Pamela Ewan, consultant allergist at Addenbrooke's Hospital, Cambridge. We wish to thank Dr Ewan for giving us the benefit of her extensive knowledge of the provision and treatment of allergy care, and for the enthusiasm and expertise with which she assisted us at each evidence session.

## What is allergy?

8. Allergy is a 'hypersensitivity' reaction, or exaggerated sensitivity, to substances which are normally tolerated. Such substances are known as allergens.<sup>7</sup> Examples of common allergens include peanuts, milk, cats, horses, medicines and grass pollens. These allergens trigger the production of a harmful antibody, immunoglobulin E (IgE). In an allergic reaction, the interaction between the IgE and the allergen causes the release of inflammatory chemicals such as histamines and leukotrienes. These cause symptoms such as sneezing, itches, rashes and falls in blood pressure; they may also cause airway narrowing, which leads to shortness of breath and wheezing, and swelling which, if in the mouth, throat or airway, causes severe difficulty in breathing. Sometimes symptoms are caused by other mechanisms, where IgE is not involved. These are often described as 'intolerances' to, for example, foods or medicines.<sup>8</sup> Allergy practice deals with both IgE-mediated and non-IgE-mediated reactions.

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7 Allergy: the unmet need, p3

8 Allergy: the unmet need, p3; Ev 145 (Alan M Edwards)

9. People commonly react to a number of allergens causing different symptoms in several parts of the body. Symptoms may be mild or severe. Reaction times may vary from immediate, to hours after exposure. Some people recover after a period of illness; others remain at risk for the rest of their lives. Some allergies vary according to the season. Many, such as those related to food or drugs, are avoidable if identified properly.

10. Allergic symptoms vary greatly. An individual may have a single symptom (for example, asthma) or multiple reactions (for example, asthma, eczema and hay fever); swellings on the skin; or sickness. The most extreme reaction of all is anaphylaxis. During anaphylaxis, the blood pressure drops, breathing becomes difficult and an individual may collapse and become unconscious. Symptoms include swelling in the throat and mouth and severe asthma.<sup>9</sup> In extreme cases those suffering anaphylaxis will die; and many more will believe during an attack that they will die. Anaphylaxis is a very frightening experience and the fear of a further reaction—particularly when a child is involved—creates great anxiety.

11. Allergy is a complicated and sometimes confusing branch of medicine. As the seminal RCP report *Allergy: the unmet need* noted, in some conditions IgE-mediated allergy plays a role in some patients but not in others.<sup>10</sup> This is especially the case for asthma, rhinitis (chronic nasal symptoms), eczema and urticaria (itchy skin blotches or hives). Seasonal allergic rhinitis, or hay fever, is entirely caused by allergy. Chronic allergic rhinitis may be caused by allergy to the house dust mite. But other forms of rhinitis are not IgE mediated. Similarly, in respect of asthma, “allergy may be just one of many triggers of an attack; others include virus infections, air pollutions or stress”.<sup>11</sup> To complicate matters further, the manifestations of allergy may alter with time: eczema and milk allergy are more prevalent in children but may abate in adulthood or be replaced by other allergies, particularly if not identified and treated at source. Finally, allergy may present in a very complicated way. Professor Stephen Durham, a consultant in allergy and respiratory medicine at Royal Brompton and Harefield NHS Trust, noted:

A major problem is that the typical allergic patient has diseases affecting the multiple organ systems including eyes, nose, chest, skin, gastro-intestinal tract with or without the risk of potential life-threatening anaphylaxis.<sup>12</sup>

12. The following diagram, from the RCP report, well illustrates the role of allergy in various diseases:

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9 Ev 2 (the Anaphylaxis Campaign)

10 Royal College of Physicians (2003), available from <http://www.rcplondon.ac.uk/pubs/books/allergy/allergy.pdf>

11 *Allergy: the unmet need*, p5

12 Ev 106

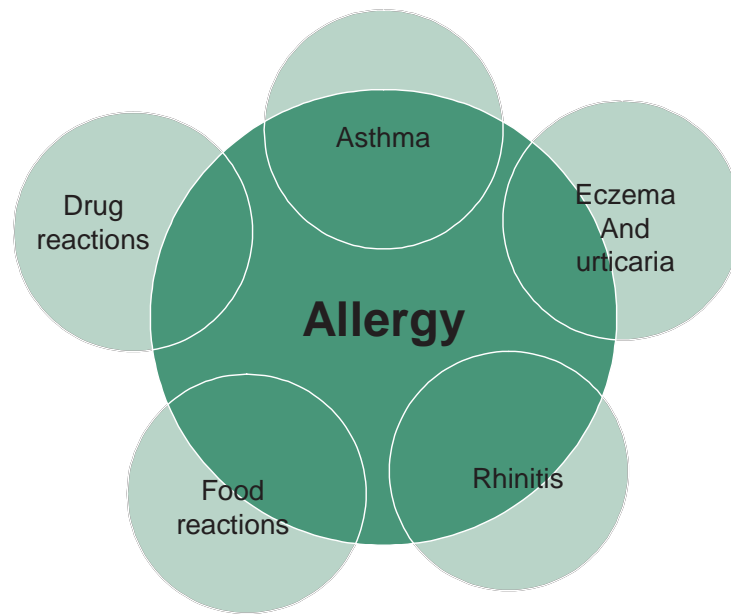


Figure 1: The role of allergy in various diseases.<sup>13</sup>

### *The role of an allergist*

13. An allergist deals with a wide range of allergic disorders which cross the conventional disciplines within medicine and also with disorders specific to allergy. Since allergy commonly presents with disease affecting different parts of the body, disorders often co-exist. Therefore, as well as having knowledge of a number of different medical specialties (which will be less comprehensive than that of specialists in these other areas), an allergist also needs to have a wide knowledge specific to allergy. This includes knowledge of allergens, causes of disorders, diagnostic methods and the natural history of disease and treatments. Thus the expertise of an allergist has to be distinct from that of organ-based specialists or immunologists. With growing numbers of people today being subject to allergic disease, the expertise and added value which comes from a proper focus on this, we believe, needs to be seen as a part of mainstream healthcare.

14. Specialist allergy nurses and dieticians are an important part of an allergy team. Nurses have a variety of roles, including supporting the accurate diagnosis of allergy through skin testing, giving advice on allergen avoidance, and training patients in the use of self-injectors. In addition, nurses will monitor patients during procedures which carry the risk of anaphylaxis—for example, immunotherapy (where increasing doses of an allergen are injected under the skin over time as a treatment to allow the patient to develop resistance to the allergen) and challenge testing (where the patient is exposed to the suspected allergen under controlled circumstances). Paediatric and adult dieticians provide valuable support when patients are on long term dietary exclusion or need to exclude foods for diagnostic purposes.

15. Allergy is treatable and manageable; often one or two visits to a specialist allergist will be sufficient. Accurate diagnosis, including identification of allergic or other triggers, is essential. Management involves avoidance of the allergen or trigger, as well as drug treatment. Avoidance may completely relieve the symptoms of the disease. For example, if a drug or food is the trigger, or if asthma is caused by a specific allergen, avoidance strategies can be identified and assembled for the individual patient. Even when allergens cannot be avoided completely, reduced exposure ameliorates chronic symptoms. An allergist needs to have expertise in controlling problems unresponsive to standard drug therapy, such as some types of asthma, rhinitis and angioedema (swelling under the skin or of the mucous membranes), as well as conditions not normally recognised or managed by others, such as food, drug and insect-sting allergies, and the prevention and planned self-management of anaphylaxis. An alternative management strategy is immunotherapy, which alters the underlying immunological abnormality and may 'switch off' disease. Other types of allergy vaccine are being developed and new treatments are expected: allergists will have an important role in patient selection and administering therapy. Allergists also need to have experience of treating acute allergic reactions, including anaphylaxis, as these can be induced by some types of allergy testing or immunotherapy.

## Trends in prevalence

### *More allergy*

16. Levels of allergy in the population have soared in recent years. Whereas, as we have noted, allergies are present in around 30% of the adult population, the figure is higher for children, with 40% of children having some form of allergy. In England, around 15 million adults and children will suffer from some form of allergy, with 10 million showing symptoms in any one year.<sup>14</sup> A recent survey in the London schools area suggested that 2% of children aged 5–18 suffered peanut allergy, 2% were allergic to other nuts and 1% suffered sesame seed allergy.<sup>15</sup> Adverse drug reactions account for 5% of hospital admissions in the UK, and drug allergy is one cause of such reactions that is becoming increasingly common.<sup>16</sup> Asthma, rhinitis and eczema have increased in incidence two- to three-fold in the last 20 years.<sup>17</sup> Dr Shuaib Nasser, a consultant allergist at Addenbrooke's Hospital, Cambridge, told us:

In an allergy clinic 10 years ago, if we saw a patient with a fruit allergy or a latex rubber allergy, we would call everyone in the clinic round to talk to the patient. All the doctors, all the nurses would come round and we would talk with great enthusiasm with the patient because this was such a rare disorder. Now we see these patients two or three times a week and there is nothing surprising about it. The health service has to evolve with the changing pattern of illness.<sup>18</sup>

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14 Ev 52 (BSACI)

15 Ev 125 (Dr Gideon Lack)

16 *Allergy: the unmet need*, pxiv

17 *Allergy: the unmet need*, pxiv

18 Q7 (Alan M Edwards)

17. Approximately 20% of the population now suffers from allergic rhinitis (hay fever, with varying degrees of severity). Alan Edwards, clinical assistant at the David Hide Asthma and Allergy Research Centre, St Mary's Hospital, Isle of Wight, provided evidence on the incidence of common manifestations of allergy using data gathered from two birth cohorts, which demonstrated the growth in allergy in the population.<sup>19</sup>

**Table 1:** Manifestations of allergy, asthma, allergic rhinitis and eczema compared in two birth cohorts

| Newborns | Asthma | Rhinitis | Allergic eczema (%) |
|----------|--------|----------|---------------------|
| 1989-90  | 8.64%  | 15.54%   | 12.55%              |
| 2001-02  | 21.58% | 25.03%   | 24.04%              |

Data source: Ev 145 (Alan M Edwards)

18. A table showing the prevalence of some common allergies is given below:

**Table 2:** Prevalence of some allergic disorders in adults and children in UK and other EU countries

|                                   | Children prevalence % | Adults prevalence % |
|-----------------------------------|-----------------------|---------------------|
| <b>Asthma</b>                     |                       |                     |
| Wheeze in past year               | 32                    | 19                  |
| Ever wheezed                      | 49                    | 32                  |
| <b>Allergic rhinitis</b>          |                       |                     |
| Rhino-conjunctivitis in past year | 19                    | 19                  |
| Hay fever ever                    | 35                    | 19                  |
| <b>Eczema</b>                     |                       |                     |
| Eczema ever                       | 24                    | 16                  |
| <b>Food</b>                       |                       |                     |
| Peanut and/or tree nut            | 2                     | Not known           |
| Peanut                            | 1.4                   | Not known           |
| Egg                               | 1.6                   | Not known           |
| Milk                              | 1.1–3                 | Not known           |

Data source: See footnote<sup>20</sup>

19 Ev 145. The figures are for the cumulative prevalence of reported asthma, allergic rhinitis and eczema among parents and siblings of the newborn infants.

20 Sources: ISAAC (the International Study of Asthma and Allergies in Childhood), *Lancet* 1998, 351:1223–32; Gupta R, Strachan D P, Anderson H R, *Clinical & Experimental Allergy*, 2004, 34:520–26; Lack G, (personal communication), Avon Longitudinal Study of Parents and Children; Grundy J, Matthews S, Bateman B et al, *Journal of Allergy & Clinical Immunology* 2002, 110:784–9; Eggesbo M, *Allergy*, 2001; Host A Ann, *Allergy Asthma Immunology*, 2002; *Allergy: the unmet need*, Appendix 1; Avery N J et al, *Paediatric Allergy and Immunology*, 2003

19. Demand on allergy services is growing. Guy's, King's, and St Thomas' School of Medicine runs a specialist allergy service which took on 1,090 patients in 1997–98, but 1,922 patients in 1999–2000. Dr Gideon Lack, a consultant in paediatric allergy and immunology at St Mary's Hospital, London, noted that at least 6% of paediatric admissions to Accident and Emergency (A&E) at his hospital over the last year were “directly attributable to an acute allergic problem”.<sup>21</sup>

20. The causes of the striking growth in the prevalence of allergies are not thoroughly established. One possible explanation has been termed ‘the hygiene hypothesis’. This argues that a lack of exposure to microbes in early life appears to encourage the development of allergy. The hypothesis is supported by evidence to suggest that the oldest child in a family has increased susceptibility to allergy. This child is more likely to be spared infections early in life, giving less opportunity for what one witness described as the “kick-starting of the immune system”.<sup>22</sup>

21. Professor Stephen Holgate, Chair of the National Allergy Strategy Group (NASG), suggested that factors potentially involved in the increased prevalence of allergy included: diminished exposure to bacterial products; dietary changes (in particular, those altering the micro-flora in the intestines); and the introduction of new allergens in the form of chemicals and ‘foreign’ proteins entering the environment and increasing sensitisation. There is also a growing debate as to whether exposure to antibiotics early in life might be a factor, by altering the bacterial flora and therefore damaging the ability of the immune response to self-generate its protection.<sup>23</sup>

### **More serious allergy**

22. In its memorandum the Department noted that “the majority of people with an allergy experience mild or moderate symptoms”.<sup>24</sup> Nonetheless, the rise in allergy has been most marked in respect of serious allergy. According to the British Society for Allergy and Clinical Immunology (BSACI) and the NASG, numbers with “complex, severe or life-threatening illnesses” are growing “disproportionately”.<sup>25</sup> The chief executive of Addenbrooke's NHS Trust, which provides an allergy service widely recognised as a centre of excellence, commented that the case-load the service in his hospital dealt with had changed, and that the majority of patients seen now had severe or complex allergies.<sup>26</sup> The RCP similarly noted:

A number of severe and potentially life-threatening disorders which were previously rare, are now common. As part of the increase in incidence, more children are now affected, particularly by previously little-known food allergies, such as peanut allergy.

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21 Ev 125

22 Q70 (Dr Lawrence Youlten)

23 Q66

24 Ev 71

25 Ev 36

26 Ev 150



These are also among the most serious allergies, and accurate diagnosis, advice and treatment are vital.<sup>27</sup>

23. Hospital admissions for anaphylaxis have increased seven-fold over the last decade, according to the Department's figures. The number of deaths caused by anaphylaxis is extremely difficult to ascertain. Dr Richard Pumphrey, a consultant immunologist at St Mary's Hospital, Manchester, has maintained a register of anaphylactic deaths since 1992, and reported that it had been possible "to confirm only 20 acute allergic fatalities each year", but that there were "reasons to believe that this is an underestimate".<sup>28</sup> It is likely that many deaths are recorded as being caused by asthma. A 1994 study of patients coming into an A&E department found that a severe anaphylactic reaction occurred in approximately one in 3,500 of the population each year in the community.<sup>29</sup> This also is likely to be an under-estimate, as the figures only included those being treated in A&E, and those whose anaphylaxis arose in the community. Anaphylaxis induced by, for example, intravenous drugs or latex in hospital settings is not included.

24. The impact of serious allergy is considerable. It is well illustrated by an account we received from a mother whose child had life-threatening anaphylaxis due to milk allergy:

*At 3 months he had a bad reaction to something in the Welcome Pack, which contained baby rice. At one point epilepsy was diagnosed (wrongly) because he was unconscious from a crumb of biscuit. At seven months he was in hospital for three days, reacting to something in a jar with milk in it. Almost immediately he had another reaction and was in hospital for 10 days. We were then fairly sure and were avoiding milk. He had another attack at about two and a half when he got hold of something; we were very lucky that time.*

*Then we got a proper diagnosis of anaphylaxis ... If it's not clear what the problem is then it's not safe.*

*I myself had anxiety attacks. I still do. It changes life for the family ...*

*People don't know the difference between allergy and severe allergy. And you don't know how a reaction will develop. They know the tingling in the throat and lips; but ... it's not clear what's going to happen next ...*

*Nobody should underestimate the effect this has had.<sup>30</sup>*

25. As this example suggests, serious allergy often causes distress to families and carers, as well as to those directly affected. The Department itself acknowledged that three million people suffer from serious allergies in the UK.

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27 *Allergy: the unmet need*, pxiii

28 Ev 116–17

29 Stewart AG and Ewan PW, "The incidence, aetiology and management of anaphylaxis presenting to an Accident and Emergency department," *QJM* 89 (1996): 859–64

30 Ev 209 (This account was taken from a survey of patient experiences conducted for our inquiry by Dr Shuaib Nasser and colleagues at Addenbrooke's Hospital, Cambridge.)



### More complex allergy

26. As well as growing more prevalent and more serious, allergy is becoming more complex in the population. The RCP report noted patients now often had disorders affecting several systems, or parts of the body, or the whole body, as in anaphylaxis:

For example, a child with peanut allergy often also has eczema, rhinitis and asthma—so-called ‘multi-system allergic disease’. Poorly controlled asthma in a patient with nut allergy is a risk factor for life-threatening or fatal reactions.<sup>31</sup>

27. Allergic problems frequently co-exist. The RCP estimated that 10% of those with allergy aged below 45 have been diagnosed with more than one allergic condition, a figure which falls to 5% for older adults. For children the figure is 11%. A study of patients with nut allergy found that 96% also had one or more of the conditions: allergic asthma; allergic rhinitis; and atopic eczema.<sup>32</sup> Nut allergy is a relatively new manifestation of allergy, and its effects and effective treatment are still being investigated and understood by allergy clinicians.

28. Complex allergy is harder to diagnose and to treat, and requires correspondingly greater expertise on the part of health professionals. This particularly applies to the newer diseases such as nut allergy and fruit allergy, where experience of seeing many cases allows a more informed approach to diagnosis and management. But it also applies to such conditions as drug allergy, where there is currently a lack of consensus on diagnostic methods, or where tests are harder to interpret. In all these areas considerable experience is essential, but there are immense benefits to patients when their clinical care is effective. Patients with severe or complex allergy will benefit from referral to a specialist allergist.

### A crisis in allergy?

29. In a Westminster Hall debate on NHS allergy services in October 2003, the Public Health Minister, Melanie Johnson MP, acknowledged that these services “needed improvement” and that “we are starting from a very low base indeed”.<sup>33</sup> According to a survey cited by the Royal College of Paediatrics and Child Health, more than 80% of GPs thought that NHS hospital-based allergy services were “of poor quality”.<sup>34</sup>

30. Numerous memoranda attested to serious deficiencies in the current service. Professor Stephen Durham, a consultant in allergy and respiratory medicine at the Royal Brompton Hospital, described allergy services as “grossly inadequate in the face of this serious public health problem that affects around 30% of the UK population”.<sup>35</sup> For Professor Adnan Custovic and Dr Andrew Bentley of the North West Lung Centre the current lack of any specialist service in their area was “highly unsatisfactory”.<sup>36</sup> Dr Chris Corrigan, a reader and consultant in respiratory medicine and allergy at Guy’s, King’s, and St Thomas’

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31 *Allergy: the unmet need*, pp xiii–xiv

32 *Allergy: the unmet need*, pp 7, 53; Ewan, PW and Clark AT, *Lancet* 2001, 357: 111–15

33 HC Deb, 14 October 2003, Col 65WH

34 Ev 130

35 Ev 106

36 Ev 94

suggested that the “availability, geographical distribution and access times for NHS allergy services” were “woefully poor countrywide”.<sup>37</sup> The BSACI/NASG joint submission used the word “vestigial” to describe allergy services.<sup>38</sup> Dr Gideon Lack said that the sharp growth in allergy in the population, coupled with enormous pressures on scant services, constituted a “national catastrophe”.<sup>39</sup> The RCP described allergy services as “totally inadequate”, contending that NHS services could not cope with the rising amount and severity of allergy.<sup>40</sup> Dr Nasser, in written evidence, suggested that the NHS had been “wrong footed” by the epidemic. Patients were only rarely tested for allergy and many were told that there were no allergy clinics and that they would simply have to “cope with their symptoms”.<sup>41</sup> Professor Andrew Wardlaw, President of the BSACI, summed up the view of the great majority of health professionals giving evidence when he told us:

For a disease which is one of the commonest diseases in the UK, which ... causes so much morbidity and a certain amount of mortality, the service is utterly derisory, and if you compare it, there are something like 26 full-time allergists in the UK, and really we should be able to have the same as chest physicians and dermatologists, where there are 500. Quite honestly I think it is a disgrace.<sup>42</sup>

31. The general picture of provision reflected in our evidence from a wide range of health professionals, points to a service which is under-resourced and overstretched, one where the basis for improvement and growth only exists in a limited number of locations across the country, and in which specialist care is provided largely by consultants in other clinical specialties developing an interest in allergy to cover the gap. This account was reinforced by the correspondence we received from patients and the evidence of the allergy charities. We were told in graphic detail of the many problems experienced by those seeking help from the services, which were caused by a lack of provision for allergy and a lack of understanding of the clinical need, including access restrictions, withdrawal of services, inequality of service provision by location, people being driven into unregulated assessments and service use, poor and inappropriate diagnoses being given and inadequate treatment and advice for patients.

32. When the RCP assessed allergy services, in *Allergy: the unmet need*, published in 2003, it found strong evidence of deficiencies in the delivery of care in the primary care sector, and a lack of specialist care in the secondary and tertiary sectors. Specialist care was completely absent in large parts of the country. The RCP also found a dearth of both training places for new consultants and of funded posts for any who were trained. It was their considered judgement that the best starting point for meeting the growing need for allergy services was to establish specialist centres of excellence in each region; use these to act as a focus and point for training primary care; and train a whole generation of specialist allergists for whom posts should be created to give allergy equivalent status to other specialties.

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37 Ev 110

38 Ev 36

39 Ev 126

40 Ev 168

41 Ev 27

42 Q79

33. In this report, we analyse the evidence we have received to see how convincing the arguments are for a major reorientation within the NHS to create a high-quality allergy service. In chapter 2 we assess the quality of allergy services in primary, secondary and tertiary care and in the independent sector. In chapter 3 we look at the capacity of the NHS to deliver services. We turn in chapter 4 to possible levers for change to address the problems we found.

## 2 Quality of NHS provision for allergy services

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34. According to the Department's memorandum, when patients present with allergies, they may follow different pathways of care, depending on the type and severity of the problem:

- Most patients with simple allergic disease will be dealt with in general practice.
- Some patients will be seen by organ-based specialists with an interest in allergy—eg in local hospitals.
- More complex cases should be seen in specialist allergy centres. Consultants in specialist centres have important links with organ-based specialists and GPs providing allergy care. Allergy care is best provided as a network, co-ordinated by specialist allergy centres.<sup>43</sup>

35. The Minister, Dr Ladyman, described the way services were currently provided:

First of all there will be a huge body of people who will be self-medicating, who will use the advice of pharmacists, NHS Direct, and will be perfectly happy controlling their allergy through self-medication processes. Then there will be those who go to their GP and the GP will feel competent to deal with their issues. Then there will be a smaller number where the GP feels that it is necessary to make a referral and the GP will make a decision as to whether that person should be seen by a generalist or by a specialist in a particular type of physical function, or by sending them to a multiple allergy specialist. In a much smaller number of cases the person will end up with a multiple allergy specialist.<sup>44</sup>

36. This benign and evidently theoretical explanation of how the NHS currently deals with allergy was directly contradicted by most of the evidence presented to us. We received over 300 submissions from individuals that detailed the experiences they, as people with allergies or as carers for people with allergy, had encountered. It is apparent to us that very many individuals have experienced poor response and treatment for their conditions and that many continue to battle against an insufficient service provision. For many people with allergy the patient pathway is blocked or frustrated at all stages. In consequence there

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43 Ev 72

44 Q145

is a direct and stark mismatch between what the Minister said should happen and the reality as reported to us. Two examples from a survey of patient experiences conducted for our inquiry by Dr Nasser and his colleagues at Addenbrooke's Hospital, Cambridge, illustrate the nature of this mismatch (patients' names have been changed, and comments by medical staff at Addenbrooke's are included):

**'Dr Edmonds'**, aged 26.

**Clinical summary :** Aspirin sensitive asthma; treated without allergy diagnosis since a small child; now controlled for the first time.

*"I wasn't referred at all for allergy.*

*I had asthma from age 5, which was GP and chest clinic treated. My asthma was difficult, with numerous A&E admissions. I was in an undergraduate seminar, and my asthma was bad, when a tutor said that he was working with a doctor who was interested in my type of asthma. They were in the same laboratory, so I went to the Addenbrooke's Allergy Clinic.*

*I did my post-graduate in Oxford. The GP there said that there was no equivalent place in Oxford for me to be referred to, so I commuted to Cambridge for treatment.*

*Now I haven't had an attack for over a year. I have to avoid fruit.*

**Comment:** Lottery of care. Poor control of asthma for many years because of failure to recognise allergic triggers and treat appropriately. Inappropriate referrals led to costs to patient and the NHS. It was luck that got this patient to an allergist.

**'Mr Halsey'**, aged 47.

**Clinical summary:** Severe hay fever; 14 years of long-acting steroid injections; 90% improvement on immunotherapy.

*"I have been a hay fever sufferer for over 20 years. After I was 27 it got progressively worse; the season went on from April to November; it was terrible; attacks might last 2-3 days; my nose was running; I was sneezing constantly; I couldn't sleep and finally couldn't work.*

*The GP prescribed all the over-the-counter drops and sprays. They made some difference, but not enough. In the end he realised that I was not an average case; and he prescribed corticosteroid injection in April each year, which would last until July, then again in July. The treatment was effective on the same day and was welcome.*

*That lasted for 11 years. In summer 1997 I had had the July injection and was playing with the children in the park. I began to limp. I didn't take much notice. But it went on for 2-3 weeks and got worse. I went to the doctor in August and he said wait, it might be a muscle sprain.*

*When it hadn't cleared by December we began to realise that it was the side effects of the steroid treatment. I was diagnosed with avascular necrosis. Nobody admits it. Nobody accepts. They say the dose I was getting is not big enough to cause it. But the accumulation must have been a factor.*

*Now I have avascular necrosis. Both my hip bones are damaged. The right is at stage 5, total collapse and needs replacement. And avascular necrosis is now present in the left hip bone.*

*I was referred to the orthopaedic department at a hospital in London in April 1998. I still go there. I am putting the operation off as long as possible; I don't want to have a series of hip replacements over the years. But it's serious discomfort ...*

*Then came the problem with what to do about the hay fever. They referred me to the Allergy Clinic at Addenbrooke's. They gave me skin tests and began desensitisation. That was 4 years ago. It seems to work. Yesterday (30 May) I sneezed once. Today is fine. I've known nothing like it before.*

*I have friends from France. In 1992 they said that desensitisation was commonly available in France; and they were surprised that I couldn't get treatment. I wish it had been available from Day 1. I have missed work and all this could have been prevented."*

**Comment:** Delayed referral for 14 years despite desperate quality of life in the summer. Serious life-long side-effects of inappropriate treatment and failure to refer to an allergy clinic. Heavy costs to the patient and to the NHS.<sup>45</sup>

37. The key conclusions reached in the Addenbrooke's survey illustrate the problems faced by patients with allergy who have a severe and dangerous disease:

- Allergy makes its presence known in very different ways.
- A common experience is that people felt they were working on their own to manage a persistent, wearing, often unpredictable and sometimes dangerous illness.
- Many people were anxious; this was more so if a child was involved.
- In every case very substantial health gain was achievable with proper medical care.
- When care was effective this came about through recognition of the needs of the whole person and of all aspects of the illness.
- The search for help through the NHS was all too often blocked at some point, often at several points, and sometimes for long periods of time, by a health service ill prepared to care appropriately for severe allergy.
- Considerable resolve (or luck) was often required to negotiate or find a way through the system of front line care and referral.
- Experiencing lack of understanding and help, people were frustrated and sometimes frightened by what they needed to face.
- People had to, and were prepared to, face long journeys to get the right help.<sup>46</sup>

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45 Ev 30–31

46 Ev 28

## Primary care

38. A patient suffering from allergy is likely to seek access to the health service through their GP. Nobody who gave evidence to our inquiry disputed that it was appropriate for the great majority of those patients suffering from allergy to see GPs in the first instance. Nor is there any serious disagreement that GPs will treat the majority of allergy patients. Maureen Jenkins, writing on behalf of the major allergy charity, Allergy UK, argued that “most allergic disease is better managed in primary care”.<sup>47</sup> She contended that primary care clinicians were likely to be the first port of call for most problems. Allergic symptoms that are not readily controlled often lead to inflammation and chronic symptoms, resulting in repeat consultations and high costs for medication over a long period of time. If patients have access to good treatment in primary care, that allows for quicker diagnosis and management of conditions, given the paucity of specialist treatment centres. Ms Jenkins pointed out that allergy often runs in families (and even where it does not, often involves other family members in the management of the condition) and that the primary care team was best placed to offer care for a group of family members. However, because of the lack of knowledge of allergy in primary care, accurate diagnosis including the identification of allergic triggers is rare.

39. Specialists in allergy treatment nevertheless concur with the necessity to treat much allergy within primary care. The BSACI/NASG joint submission, drew attention to many shortcomings with current provision in that area, but acknowledged that “major parts of a disease with such widespread prevalence” must be treated in this sector.<sup>48</sup> Dr Nasser, from Addenbrooke’s, agreed that “five out of six [patients] can almost certainly be treated in primary care”.<sup>49</sup> This represents an ideal, and one which we believe could be realised if primary care were playing its part within a comprehensive service. But at present the knowledge-base across the whole of the NHS, including primary care, is inadequate. The Department’s memorandum made no reference to any deficiencies in the treatment of allergy in primary care. It noted the inclusion of a specific quality indicator for the treatment and care of people with asthma in the new General Medical Services contract. More generally, it pointed to the growth of investment in primary care, and the potential of this additional investment to improve the quality of care for patients.<sup>50</sup> However, we received powerful evidence to suggest that general measures are not going to tackle the specific problems of allergy in primary care, and that nothing effective is being done to correct the situation.

40. Our sample of 201 (out of 338) allergy sufferers submitting evidence, analysed in the Annex, is clearly not necessarily representative. Nevertheless, we find it very disturbing that only 23% of patients received a correct diagnosis of allergy when they first presented to their GP. The majority received an incorrect diagnosis and many visited their GP on numerous occasions over a period of years before a correct diagnosis was made. In the survey, many patients (58%) had not been referred to any type of allergy service. Sometimes they had only been referred to one after they had consulted an allergy charity

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47 Ev 124

48 Ev 34

49 Q32

50 Ev 72



and armed themselves with the names of relevant consultants and units. A lack of knowledge of allergy in primary care was noted in our analysis as being one of the principal causes of distress to patients. In addition, many patients reported a response of scepticism, ridicule and disbelief on the part of GPs when confronted by patients with suggestions over their symptoms. This confirms a point made by Dr Penny Fitzharris, consultant in allergy at Guy's, King's, and St Thomas' Trust, London, that "in the past there has been a perception amongst poorly informed medical practitioners that much allergy is in the mind and without clearly defined causes and thus services are unnecessary".<sup>51</sup>

41. Allergy UK told us that people with allergy had reported that GPs evinced little understanding of the impact of allergy on a patient's life or the potential seriousness of an "on-going allergy problem". They cited a survey that they had conducted for their 2003 report, *Stolen Lives*. Of 6,000 helpline callers questioned, almost three-quarters said they had never been asked by their doctor or nurse how allergy affected their quality of life.<sup>52</sup>

42. Allergy UK and the Anaphylaxis Campaign suggested that the commonest calls to their help-lines related to difficulties patients experienced in obtaining help with allergies in primary care. This is also clear from the patient pathway chart in the RCP Report, based on information from patients given to the Anaphylaxis Campaign.

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51 Ev 166

52 Ev 1

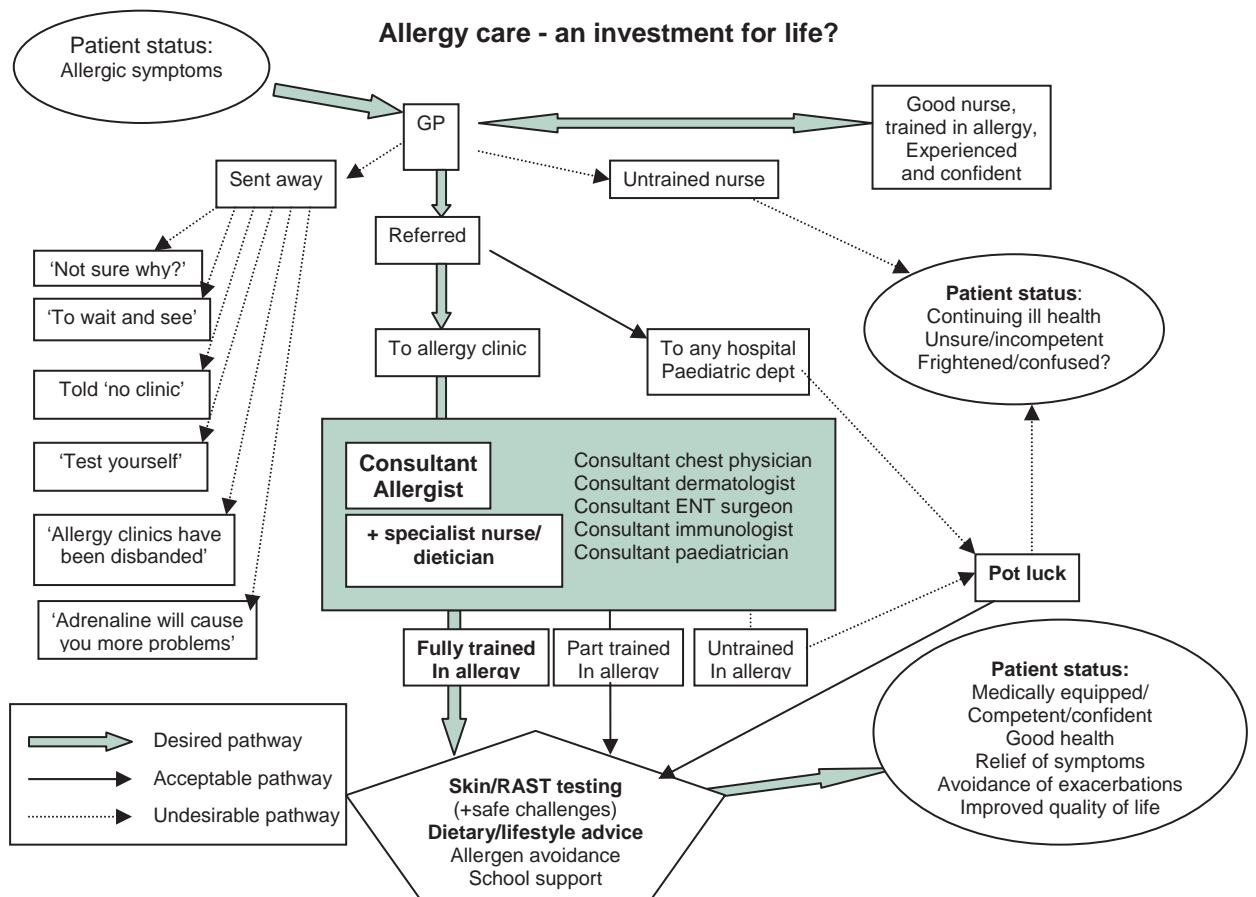


Figure 2. Allergy Pathways<sup>53</sup>

43. We also received evidence from clinicians to support the patient experiences we have had reported to us, that the primary care treatment of allergy is poor. This indicated a general absence of both willingness and expertise to diagnose, treat and refer allergy appropriately in primary care. As Professor John Warner noted, “at primary care level, allergy avoidance advice is given without doing any tests which, of course, is totally inappropriate”.<sup>54</sup> For too many patients the GP is part of the problem, not the route to a solution, as the Addenbrooke’s survey made clear, where many patients reported that the GP had not been able to treat them satisfactorily or refer them appropriately. Professor Stephen Holgate, for the NASG, painted a worrying picture when he told us that one of the most important findings of the RCP report into allergy services was that “general practitioners, across the country, were very poorly informed about allergy and generally they just reached for the anti-histamines or steroids to treat patients instead of establishing a diagnosis, which all doctors should really do as a primary move”.<sup>55</sup> A survey of 240 GPs commissioned for the RCP report revealed that the majority had “received no training in the management of allergic disorders” and that fewer than a quarter reported that they were “familiar with any guidelines for the management of an allergic condition”.<sup>56</sup> The survey revealed that:

53 *Allergy: the unmet need*, p22

54 Ev 58

55 Q72

56 *Allergy: the unmet need*, p13



- Fewer than 8% of respondents said they had access to a fully comprehensive NHS allergy service
- 59% felt that the quality of care in primary care was poor
- GPs felt most confident in treating the most common allergies eg asthma, allergic rhinitis and eczema and less confident about managing allergy in children, food or insect-sting allergy
- Skin prick tests were available in only 4% of the practices sampled
- Half of the GPs sampled had received some training in allergy theory, mostly minimal, at undergraduate level and not in clinical application. Only 10% of partner GPs and 17% of practice nurses had received any clinical training in allergy.<sup>57</sup>

44. Professor Aziz Sheikh, Professor of Primary Care Research and Development at the University of Edinburgh, pointed out that: “There is an increasing body of evidence to suggest that primary care provision of allergy services is frequently sub-optimal ... particularly with respect to the rarer (and often more severe) allergic conditions such as anaphylaxis but also in relation to milder conditions such as hay fever”. He concluded by providing a possible rationale for this situation: “Key underlying reasons for this sub-optimal care are the dearth of training opportunities—at both an undergraduate and postgraduate level—in the management of allergic problems and the lack of appropriate diagnostic facilities (eg skin prick testing) in primary care”.<sup>58</sup>

45. Dr Nasser told us that: “General practitioners are not educated in allergy. Medical students are not educated in allergy. They do not understand the concept of multi-system disorder which is becoming increasingly more severe”. He continued:

Many general practitioners in this country do not know that there are allergy services and they deny their patients because they say, “Look, we do not know where we can refer you.” And locally they may not have allergy services. They do the next best thing and, after a lot of cajoling —because they often deny the patient any referral at all—they may refer the patient to a dermatologist who may then refer them on to an ENT [Ear Nose and Throat] surgeon who may then refer them on to a chest physician or a paediatrician. This means a very tortuous journey for the patient and it is only the very determined few ... who can navigate their way through the jungle.<sup>59</sup>

46. For Muriel Simmons, Chief Executive of Allergy UK, GPs were failing to refer patients effectively to appropriate secondary or tertiary care. She told us that:

The major problem is getting a referral. ... The general practitioner, because they do not have training in allergy, are either very dismissive or they will try to find out

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57 *Allergy: the unmet need*, p14

58 Ev 194

59 Q8

where an allergy clinic is but then it is often down to a funding issue or a distance issue.<sup>60</sup>

47. With an inadequate service available in both primary and secondary care, the relationship between primary care and the secondary and tertiary sectors is highly problematic. Our evidence suggests that the primary care sector is not referring patients to secondary and tertiary care other than in areas where specialist clinics operate, and even then only patchily. In the view of the RCP, and many others submitting evidence to us, the lack of awareness and expertise in the primary care sector could only be addressed effectively after specialist care expertise was first developed across the country. This would allow primary health care professionals the opportunity to observe and learn from best clinical practice and would also act as a resource to which primary care professionals could turn for guidance and support. Dr Chris Corrigan at Guy's, King's, and St Thomas' NHS Trust argued forcefully that the lead had to come from the specialist sector:

Although the front line of allergy management will be in primary care, with no primary care skill base from which to work, clinical leadership must come initially from specialist centres.<sup>61</sup>

48. Dr Nasser, from Addenbrooke's, supported this:

I think the important thing here is that we have to say, "Who is going to train the GPs?" first. You do need a hospital base. In every region there has to be a hospital base in order to provide the training for general practitioners.<sup>62</sup>

**49. We believe that primary care should be the frontline provider of allergy care, but the skill base from which to build an adequate primary care service is lacking. In order to develop an appropriate primary care service, an infrastructure of specialist allergy services is therefore first required. As we propose below, it is imperative that specialist clinics for the treatment of allergy should be developed across the country, so that these can become centres of local networks of competent practice in allergy care, and facilitate the training and professional development of staff in primary care. It will, however, take several years for these centres to be fully operational. So we recommend below a number of measures intended to have a more immediate effect on the capacity of primary care to deal with the growing problem of allergy in the population.**

**50. We believe a national primary care allergy network should be created to support those working in primary care to allow them to access second opinions, to offer peer review of services and to provide ongoing education and professional development. The active involvement of current and developing specialist centres is crucial to the existence of such a network. We recommend that the Department takes steps to draw to the attention of GPs the directory of allergy services produced by the British Society for Allergy and Clinical Immunology.**

**51. We recommend that in its next review of the clinical incentives in the current GP contract, the Department should introduce clinical quality markers for allergy.**

60 Q12

61 Ev 112

62 Q32

52. **Primary Care Trusts should consider how to ensure that people with allergy in their area know who is appropriately trained and who is clinically accountable for providing a service. We recommend that a named person in each PCT should be identified. This process should be overseen by Strategic Health Authorities as a regional overview will be important.**

53. **We recommend that the basic training curriculum for GPs should be reviewed, and modified as required, to take account of the need to have allergy as a basic component in the initial training for general practice.**

54. We note the evidence presented by Dr Adrian Morris, a GP with particular interest in allergy, who explained that a number of organisations already offered accredited training courses for GPs and Practice Nurses, including the National Respiratory Training Centre in Warwick, Allergy UK (who hold Allergy Masterclass Training Days), Southampton University (which offers an MSc course, attended mainly by GPs) and the BSACI.<sup>63</sup> Such courses appear to be very popular. Muriel Simmons, for Allergy UK, told us that her organisation would shortly be holding two masterclasses: “Both are oversubscribed, all from GPs wishing to learn more about how to help patients in allergy”.<sup>64</sup> By taking a role in the provision of these courses, the Department would give quality assurance.

55. **We recommend that the Department should disseminate information to all PCTs on training provision in their area. Given the general level of ignorance of allergy in primary care we recommend the Department should provide some financial support to provide access to initial in-service training for a wide range of health professionals. We recommend that the Department assesses the quality of the various training courses on offer to GPs.**

### **GP<sub>s</sub> with Special Interest**

56. As a way of improving the capacity of primary care to deal with allergy, Dr William Egner, a consultant immunologist at Sheffield Teaching Hospitals Trust, suggested that the Department should urgently consider adding allergy and immunology to the list of specialties for GPs with special interest (GPwSI).<sup>65</sup> Professor Holgate, for the NASG, agreed that such a change would be beneficial:

Allergy is a discipline that would lend itself very nicely to the GPwSI system and specialists within groups of general practices that could concentrate effort and involve some nurses working in primary care ... We have GPwSIs in diabetes and other areas. So one step government could take is to recognise this as an area [in which] they might be able to support allergy specialists in the secondary care sector.<sup>66</sup>

57. GPwSIs were introduced to the Health Service in *The NHS Plan* (2000), which envisaged that by 2004, up to 1,000 GPwSIs would be “taking referrals from fellow GPs for conditions in specialties such as ophthalmology, orthopaedics and dermatology” and

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63 Ev 160

64 Q47

65 Ev 116

66 Q120

undertaking some diagnostic procedures such as endoscopy.<sup>67</sup> It is estimated that there are now at least 1,250 GPwSIs in the NHS.<sup>68</sup>

58. GPwSIs are general practitioners with a specific interest and competence in what are normally hospital-delivered services. They may deliver services for one or more PCTs beyond the scope of normal general practice, undertake advanced procedures or develop a service. Where GPwSIs are available, other GPs can refer relevant patients to them rather than to a hospital consultant. GPwSIs will often have shorter waiting times than hospital consultants and provide care within the familiarity of a community setting. They may refer patients with more serious conditions on to hospital. GPwSIs continue to be primarily generalists, with the specialist role only supplementing the duties of a regular GP.<sup>69</sup>

59. The role of GPwSI has the potential to break down some of the barriers between community and hospital-led care, enabling a more 'joined-up' system from the patient's point of view. The Action on ENT Programme, which piloted GPwSIs in ENT in Ealing, demonstrated some of the benefits of GPwSIs, including:

- 30–40% of referrals to secondary care could have been seen by a GPwSI with appropriate training, support and equipment;
- a GPwSI seeing 10 patients in an established once-a-week clinic can perform up to 500 consultations a year, seeing between 320–400 new patients annually;
- GPwSIs discharged around 70–80 % of patients back to the care of their GPs;
- GPwSI clinic consultations were significantly less costly than consultant consultations.<sup>70</sup>

60. GPwSIs are potentially beneficial to patients, but the effectiveness of a scheme may depend heavily upon implementation, accreditation and monitoring of standards, which is mainly the responsibility of PCTs. GPwSI programmes have been most successful where they are a joint PCT and Acute Trust initiative<sup>71</sup> as GPwSIs require direct access and support from consultants and the diagnostic provision sometimes only the acute sector can provide. Again, this points to the necessity of first developing specialist allergy services to support the primary care sector. In addition, established guidelines state GPwSIs should be expected to undertake at least one session a month working in the acute sector.<sup>72</sup>

61. The GPwSI National Development Team has developed a number of frameworks for the appointment of GPwSIs, laying out their responsibilities, and defining what level of qualification, formal and/or experiential, is appropriate and necessary and what evidence is required to prove this. Currently, these guidelines cover under 20 specialties; a survey of

67 Department of Health (2000) *The NHS Plan: A Plan for Investment, a Plan for Reform*

68 Department of Health/NatPaCT (2003) *Practitioners with Special Interests: bringing services closer to patients*

69 Department of Health and Royal College of General Practitioners (2002) *Implementing a scheme for General Practitioners with Special Interests*

70 Sanderson, Diana (2002) *Evaluation of the GPs with Special Interest (GPwSI) Pilot Projects with the Action on ENT Programme* (York Health Economics Consortium)

71 Department of Health/NatPaCT (2003)

72 For example, Department of Health (2003) *Guidelines for the appointment of general practitioners with special interests in the delivery of clinical services: diabetes*

GPs has shown that there is interest in many more, including specialised allergy services.<sup>73</sup> The prioritisation of development of GPwSI guidelines for certain services over others is based upon services with national programmes such as those with National Service Frameworks, for example coronary heart disease and diabetes, or services that present access problems for many patients, such as drug misuse or mental health provisions. However, even within some of the more specific guidelines, much of the detail of individual GPwSIs is to be determined locally by the PCT holding the contract.

**62. We conclude that, while GPs with Special Interest could make an important contribution to service development in allergy care, a precondition of their successful introduction is the prior availability of specialist care to underpin standards and provide clinical training and case management guidance. Nevertheless, the curriculum for GPwSIs could be developed with allergy consultants now, and we recommend that this should be done. The pace of change can then be set taking account of the overall programme required to modernise allergy care within the NHS.**

**63. We recommend that the GPwSI National Development Team begin work on a framework for GPwSIs in allergy services, working with the current specialist allergy centres (and with additional regional centres once these are established) to identify the core activities of an allergy GPwSI, and the qualifications and/or experience that would make a GP eligible for such a position.**

**64. To show that it is genuinely committed to this planning phase, the Department should indicate that it wishes to see (and is prepared to finance) the creation of a first generation of GPwSIs in allergy on a sufficient scale to ensure there is a GP with a special allergy interest in each PCT, once sufficient consultants in allergy are available to train them.**

## Secondary and tertiary care

65. For some time to come, the majority of patients referred to secondary care will not be treated by an allergy specialist. As the RCP report explained:

Much of allergy is treated by organ-based specialists, dermatologists, and more recently by immunologists and paediatricians. The majority have no formal training in allergy and because their training tends to be in a restricted area, it does not provide the multi-disciplinary approach necessary to manage patients with allergies.<sup>74</sup>

66. Professor Stephen Durham, a consultant in allergy and respiratory medicine at the Royal Brompton and Harefield Trust, outlined some of the limitations of using organ-based specialists to treat allergy:

The current piecemeal service provided at secondary care by individual organ specialists is inadequate. For example, a chest physician may be competent to evaluate the allergic component of asthma. He may or may not recognise that the

73 Jones R and Bartholomew J (2002) 'General practitioners with special clinical interests: a cross-sectional survey', *British Journal of General Practice* 52: 833–34

74 *Allergy; the unmet need*, p21

patient has associated distressing allergic rhinitis requiring separate management. Almost certainly, he would not be equipped to investigate and diagnose associated food allergy. Neither could he deal with associated urticaria or difficult eczema. Such a patient requires one consultant allergist with a multi-disciplinary approach to diagnosis and treatment rather than the alternative, namely 4–5 organ specialists to deal with multiple allergic problems.<sup>75</sup>

67. Overall, the BSACI described national capacity to manage allergy in secondary care as “derisory” and noted that such capacity as was available was “provided in large part by specialists in other disciplines”.<sup>76</sup> They suggested that when care was provided by non-specialists, the allergic basis of the disease would not be addressed, and the clinics would not be equipped to deal with several different expressions of allergy, leading to “sub-optimal management”. Apart from consultant allergists, the two main specialties seeing patients with allergic diseases in roughly equal numbers are clinical immunologists and respiratory physicians. The BSACI noted that both these specialties did include the management of allergic disease as part of their training (though this was more the case with immunologists than with respiratory physicians). While some immunologists regarded patients with allergy as their main interest, in the view of the BSACI:

The majority of clinical immunologists and respiratory physicians have a considerable workload caring for patients with diseases relevant to their main interest (managing the immunology laboratory and immunodeficiency in the case of clinical immunologists and chest disease for respiratory physicians) and do not have the time or often the inclination to develop allergy services.<sup>77</sup>

68. In evidence to us, Dr Ladyman questioned whether there was in fact a clear consensus that patients requiring specialist allergy treatment ought to be referred to an allergy specialist:

What I would counsel you about is that I think there was an implication from some of your earlier witnesses that there was a consensus view about the benefit of specialist centres. I do not believe that there is that consensus view; I believe, for example—and I think that you have had written evidence to this effect from some of the other specialist areas—that dermatologists take the view that if you have a skin condition or eczema you should start off with a dermatology specialist rather than going to a multiple allergy clinic. Dieticians take the view that you would be better off seeing a dietician first. There are some specialists in respiratory diseases who think that if you have asthma you ought to start off with lung specialists and respiratory specialists. The impression I got from some of your earlier witnesses was that what they would like to see was a direct referral of people from their GP to their allergy specialists, and I think that is probably appropriate where there is clear evidence that the person is suffering from multiple allergies, but it is not necessarily the best thing to do if it is clear that the allergy they are suffering from is more specific than that.<sup>78</sup>

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75 Ev 106

76 Ev 54

77 Ev 54

78 Q130



69. However, our evidence was almost uniform in calling for specialist allergy treatment for people with severe or complex allergy. The British Association of Dermatologists in their memorandum, which the Minister referred to, did not argue against the creation of specialist allergy centres, but merely remarked on the limitations in allergy services which some departments of dermatology were able to provide.<sup>79</sup> Dermatology was one of the disciplines represented on the RCP working group that produced the report *Allergy: the unmet need*, which the Council of the College as a whole sanctioned. If, as the Minister claimed, there is a serious debate about whether allergy should be dealt with by allergists or organ-based specialists, we find it surprising that only one or two of the 400 or so memoranda we received had anything at all to say about this and none argued directly against it.

70. Our evidence indicates therefore that the RCP analysis and recommendations are not contested, as Dr Ladyman suggests. A need for specialist allergists is recognised and accepted within the medical profession. Nor does there seem to be any serious disagreement about the way allergy overlaps with other specialties, especially respiratory medicine and dermatology. The complementary nature of the relationships seems to be recognised and, for example, it seems generally accepted that it is appropriate for asthma and eczema to be dealt with primarily by these specialists. There seems also to be a professional consensus, unfortunately one not acknowledged by the Minister, as to the added value provided by an allergist. For patients where allergy is a driver of the illness, an allergist can identify the trigger; and a clinical judgement that there is, or may be, such a trigger, or that this needs to be ruled out, determines when an allergy specialist is needed. This is usually either for severe disease, or when there is multiple system involvement, or for diseases that do not sit in any other specialist's territory, for example food, drug and insect-sting allergy, anaphylaxis and some types of angioedema. But it can sometimes be appropriate to refer to an allergist for a single system presentation if there are specific clinical presentations. We consider that the RCP were right in identifying the need to provide increased specialist capacity in allergy care given the (undisputed) growth in allergic diseases.

71. We asked the Minister how the conflict of views he had depicted as existing between organ-based specialists and allergy specialists could be resolved. We did not find his answer especially reassuring, given that there is a consensus and none of the evidence demurred from it:

Ultimately these things, I suppose, get resolved. If there is no growing consensus on the way forward then these things do get resolved by national guidance, like National Service Frameworks being produced in order to say, "Here is the model that we think is the best evidence-based way forward". How these things normally get resolved is through processes like the one we are undertaking today, the publication of the Royal College's documents and a review of services by local commissioners and discussions with clinical specialists in order to come to something that approaches the consensus of the best way forward. I know that does not sound terribly clean but the alternative

is something which I think would be less effective ... and that is for me to sit in my office in Whitehall and make these decisions for you all.<sup>80</sup>

72. International comparisons suggest that the UK is out of step with other countries in terms of the numbers of its doctors specialising in allergy. For example, while there are only four NHS paediatric allergists in the UK, in Sweden, there are 96 trained paediatric allergy specialists and, in Germany, there are 500. Compared with the UK, there are five times the number of paediatric allergists in Greece and four and a half times the number in Switzerland.<sup>81</sup>

73. When giving evidence to us Dr Nasser told us:

We are seeing here that there is a lack of allergy specialty. This is something that is available and many of the other developed countries in the world, throughout Europe, the United States, have very well developed allergists who can treat multi-system disease. In this country we need to get education, starting from medical school upwards. We need to train doctors to become allergists and we need to develop centres of excellence where allergy is a recognised specialty.<sup>82</sup>

74. The lack of development of allergy services in the NHS in comparison to other European countries was illustrated to us by Professor Holgate, for the NASG, who suggested that “we should be able to lift the whole thing up, as has happened in every single country in Europe, apart from Great Britain; even Estonia, Latvia and Lithuania have allergy practitioners”.<sup>83</sup> Dr Penny Fitzharris, a New Zealander recruited to the NHS, noted the absence of UK-trained candidates to take over her role as consultant in allergy at St Mary’s Hospital in Paddington in 1993 and at Guy’s Hospital in 2004, and argued that allergy services were “much better developed in Continental Europe, North America and Australasia” than in the UK.<sup>84</sup>

75. As other countries have discovered, for allergy as it is now presenting, the best and most efficient referral path is often not, as the Minister suggests, GP to another specialist and then to an allergist, but often GP straight to an allergist. Where specialist services exist, GPs appear to recognise this: approximately 85% of referrals to such centres are made direct from primary care. At the moment, however, an unusual situation prevails in the NHS. There are very few allergists, and nearly all are acting in both a tertiary and secondary capacity (for the most part, providing a local specialist service for their geographical area). But some patients travel very long distances out of area to obtain care. In the rest of the country, secondary care is mainly being provided by other types of consultants, who have other work to do and who are either limited in their expertise of allergic conditions, or have expertise limited to one part of the body, or both. We are not convinced that this is an efficient or an effective model. Even when they eventually find their way to appropriate specialist care, the journey for many patients has to be through the hoops of partial or, to varying degrees, inappropriate care. And for the majority not even this possibility is

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80 Q209

81 HC Deb, 14 October 2003, col 63WH

82 Q6

83 Q72

84 Ev 166



available. They have no choice; effectively they have no access to any kind of adequate NHS allergy care.

76. Turning to the specialist centres that do exist for the treatment of allergy, what is immediately striking is the absence of geographical equity in provision. There are only six full-time allergy clinics in England and none in Scotland, Wales or Northern Ireland. The six clinics in England are located at:

- Guy's Hospital, London
- Royal Brompton Hospital, London
- St Mary's Hospital, London
- Addenbrooke's Hospital, Cambridge
- Southampton General Hospital
- Glenfield Hospital, Leicester.

77. These six centres provide expertise in all types of allergic disease, including complex problems, and provide a comprehensive allergy service with a multidisciplinary approach. The clinical service provision is complemented by an international reputation for research in allergic disease. There are nine part-time services run by specialists and 86 part-time services offered by consultants in other specialties (these are generally part-time clinics).<sup>85</sup>

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85 *Allergy: the unmet need*, pp 24–25

78. The map below, taken from the RCP report, indicates the distribution of full- and part-time specialist centres, and the specialist allergy clinics:



79. The Department, in its memorandum, acknowledged the existence of these six full-time and nine part-time specialist centres but we find it surprising it chose not to discuss how what they represent could be developed into a fairer national system of care. We also find it most surprising that the Department nowhere in its evidence acknowledged what Professor Holgate described as the “tremendously poor distribution and inequality of allergy service provision”, which had contributed towards a “tremendous mismatch between clinical provision of services and the clinical need”.<sup>86</sup>

80. The RCP in its report *Allergy: the unmet need* recommended that all of the former eight NHS regions in England, serving populations of around five to seven million, should have a minimum of one specialist allergy centre. They recommended minimum staffing levels for each centre of:

- two adult allergy consultants
- two paediatric allergy consultants supported by paediatric nurse specialists
- two full-time nurse specialists
- one half-time adult dietician and one half-time paediatric dietician with specialist training in food allergy
- facilities for training of two specialist registrars (in some centres only).

81. The cost of such an expansion has been estimated at £5.6 million per annum.<sup>87</sup> We believe that much of this cost would be offset by the introduction of more effective and efficient treatment of allergy. Better care which tackled the cause of the disease would lead to a reduction in the long-term prescription of drugs which treat symptoms, reduced hospital admissions and A&E attendance, and fewer GP consultations for ongoing poorly controlled disease. It would relieve the pressures on other specialist services. As the BSACI/NASG in their submission suggested, the current management of allergy, where patients often attend separate clinics for different problems, is “wasteful of NHS resources”.<sup>88</sup>

82. Allergic disease currently accounts for 6% of general practice consultations, 0.6% of hospital admissions, and 10% of the GP prescribing budget. Allergic problems are responsible for an estimated 12.5 million GP consultations a year (with an estimated cost of £211–311 million). The cost (in primary care, excluding hospital services) to the NHS is £900 million per annum.<sup>89</sup> Hospital admissions have been costed at over £68 million per year, but none of the outpatient work, which is the main hospital cost of allergy, has been determined.

83. The chief executive of Addenbrooke’s Hospital, which maintains a major allergy clinic, suggested that more specialised treatment of allergy would be “a cost effective system for the NHS at large, preventing ongoing illness and reducing further acute reactions”.<sup>90</sup> Dr

86 Q72

87 Ev 39 (NASG/BSACI)

88 Ev 40

89 *Allergy: the unmet need*, p xiv

90 Ev 151

Michael Tettenborn, a consultant paediatrician at Frimley Children's Centre in Camberley, contended that: "Our current approach of simply prescribing anti-histamines and steroids in most instances is not cost effective and is associated with significant problems with side effects. An investment in this area could save the NHS money as well as reducing mortality and significant morbidity".<sup>91</sup> Further, the cost is more than a service saving. It represents a service development investment. Developing specialist allergy services will lift the service in the whole region and the capacity of all providers by having expertise 'on tap'.

84. It seems to us to be manifestly inequitable that there is no comprehensive allergy service in England north of Manchester or west of Bournemouth.<sup>92</sup> The current provision in fact owes nothing to the geographical spread of allergy in the population. Rather, it comprises those centres where specialist research in allergy has taken place, on the back of which clinical services have developed *ad hoc*.<sup>93</sup>

85. We endorse the proposal of the Royal College of Physicians that a minimum of one specialist allergy centre should be established in areas equivalent to each of the former NHS regions, serving populations of five to seven million, to offer at least some local expertise for allergy sufferers. More provision may well be needed in less densely populated areas. We also endorse their recommendations for staffing levels both for adult and paediatric care, that is to say that each centre should have as a minimum two adult allergy consultants, two paediatric allergy consultants supported by paediatric nurse specialists, two full-time nurse specialists, one half-time adult paediatrician and one half-time paediatric dietician. This is our key recommendation and the one on which all other elements to develop a national allergy service within the NHS will depend.

86. The specialist allergy clinics, other clinics capable of providing allergy services and hospital trusts need to develop new ways of working, or adapt old ways, to provide for a national network of interim care while a new cohort of allergists who will run these new centres is trained. Through these networks, the information could be gathered to locate new consultant allergist posts where unmet need is greatest as new doctors emerge from training. We believe that Strategic Health Authorities should play their part in co-ordinating such activity.

87. In the longer term, we would like to see allergy provided with a full specialist consultant workforce. The Royal College of Physicians' medical workforce projections indicate this would eventually require the creation of around 520 consultant allergist posts. This is clearly an ambitious goal and unachievable even in the medium term when starting from such a low base, even if the resources were available. We recommend that an important more intermediate target would be for most major teaching hospitals to have a consultant allergist-led service, covering adult and paediatric allergy, with appropriate support staff.

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91 Ev 92

92 Ev 35 (NASG/BSACI)

93 Q73 (Professor Holgate)

## Services for children

88. As we have noted, prevalence of allergy in children is higher than it is in adults. Allergy poses particular problems for children. It can, for example, disrupt their school lives. A regime of anti-histamines to combat hay fever is not the ideal preparation for exams. The need for constant vigilance on the part of those allergic to nuts is not assisted if schools cannot treat anaphylaxis or cannot adequately protect children against allergic triggers. One study has suggested that children with peanut allergy are more anxious about their condition than are those with insulin-dependent diabetes.<sup>94</sup> It has also been estimated that 3–6% of 13–14 year olds suffer from sleep loss as a result of eczema or asthma.<sup>95</sup> Many children with allergic disorders also suffer from bullying and social segregation at school.<sup>96</sup>

89. There is evidence to suggest that early diagnosis and treatment of allergy can reduce the disease burden in later years. Professor Tak Lee, of King's College London, informed us that:

Early treatment of paediatric allergy with, for example, immunotherapy may reduce the progression of disease and reduce new allergic sensitisations. There is therefore a real opportunity to halt the epidemic of allergic disease if the appropriate services and resources are provided.<sup>97</sup>

90. As a practical example of this, Dr G K Scadding, a consultant allergist and rhinologist at the Royal National Throat, Nose and Ear Hospital told us that rhinitis was a risk factor for asthma development, and that treatment of childhood rhinitis by immunotherapy could reduce progression to asthma.<sup>98</sup>

91. Professor John Warner, a paediatric allergist at the University of Southampton, indicated the scale of the problem. He felt that allergy in childhood required the same network of specialist tertiary centres supporting other health professionals with specific training as should be present for allergy in adults. He told us that the potential demand for specialist treatment was enormous:

We estimate about a sixth of the total number of cases require special attention. In childhood now 40% of all children have some allergy. Of those, about a sixth require specialist referral, and that means we are talking, based on the current birth rates, about 40–45,000 new cases a year for specialist referral.<sup>99</sup>

92. The estimate—that with each new birth cohort, a potential 40,000 children with allergy will be added to the problem each year—was made by the NASG, in the document *An NHS Plan for Allergy—Making a Start*.<sup>100</sup> This document made proposals to improve allergy care, and was sent to Dr Ladyman in May 2004. Professor Warner only quoted one aspect

94 Cited Ev 4

95 Cited *Allergy: the unmet need*, p7

96 *Allergy: the unmet need*, p10

97 Ev 109

98 Ev 183

99 Q115

100 See Ev 36ff

of the estimate. The other is the gap between provision (including all providers, not just allergy specialists) and need. Taking all measurable factors into account, it was estimated that hospital provision can only deal with about 2% of the need (all ages). With current capacity for allergy referral (to all types of consultant) it would take 50 years to clear the backlog. Even taking account of the inevitably rough and ready nature of these estimates, the orders of magnitude they expose are exceptionally worrying and point to an unacceptable situation.

93. In the UK, a high percentage of both inpatient and outpatient paediatric workload is related to allergic disease. In a recent survey of paediatric A&E admissions at St Mary's Hospital, London, almost 7% of children seen as emergencies were diagnosed as having allergy disorder. These children required twice the rate of admission and twice the rate of specialist tertiary referral compared to other children attending as emergencies.<sup>101</sup>

94. Notwithstanding the scale of the problem, our evidence suggests that services for children are even more scant than they are for adults. Dr Gideon Lack, a consultant in paediatric allergy and immunology at St Mary's NHS Trust, London, argued that children were suffering the consequences of not seeing paediatric allergy specialists in three ways:

Firstly, they are denied proper diagnosis and care. These children are at risk of anaphylactic reactions (one in 50 children in the UK are allergic to peanut and similar numbers of children are allergic to tree nuts).

Secondly, these children suffer nutritional consequences in the absence of adequate nutritional advice. They exclude multiple foods and have compromised diets. We have seen children with rickets, growth failure, developmental disorders and severe psychological problems all because they failed to receive proper specialist advice at the right time.

The third way in which these children suffer damage is that their parents are unwillingly forced into the hands of dangerous alternative practitioners who run private clinics where non-validated and often dangerous practices are used. I know of instances where patients have been morally blackmailed to receive expensive treatments that are potentially life threatening. The situation is analogous to the days when young pregnant women were forced into the hands of back-street abortion clinics.<sup>102</sup>

95. According to the Royal College of Paediatrics and Child Health (RCPCH), the majority of care for children with allergies is provided by organ-based specialties, ENT surgeons and dermatologists, with no allergy training. This, in their view, leads to "inappropriate care, bizarre and poor practice".<sup>103</sup> Only four centres, St. Mary's Hospital and King's College Hospital in London, Southampton General Hospital, Glenfield Hospital and Royal Infirmary Hospitals, Leicester, offer a full range of paediatric allergy services. As we have noted, Sweden, a country with a population less than a sixth that of the UK, has 96 trained allergy specialists. Against this, the UK has six paediatric consultants. In the view of the

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101 *Allergy: the unmet need*, p9

102 Ev 125

103 Ev 130

RCPCH, provision in the NHS is “totally insufficient” to meet the need. The situation seems unlikely to improve in the near future, since there is currently only one trainee in paediatric allergy.<sup>104</sup>

96. The RCPCH also recommend the creation of a new cadre of general paediatricians with an interest in allergy in teaching hospitals and district general hospitals to deal with local needs, and the designation of one community paediatrician in each PCT to co-ordinate the management of children in schools and nurseries at risk of severe allergic reaction. Dr Vibha Sharma, a consultant paediatrician in the Royal Albert Infirmery, Wigan, called for the appointment of a consultant with special interest in allergy in each district general hospital, linked to a regional tertiary centre to provide expertise and support. She noted that when she had taken over an embryonic paediatric food allergy clinic she had found it very difficult to obtain expert clinical support and training for her work.<sup>105</sup>

97. Such provision as is available is usually patchy, poorly co-ordinated and under-resourced. Dr Julia Clark and Professor Andrew Cant, consultants in paediatric immunology at Newcastle General Hospital, recently undertook an assessment of paediatric allergy work carried out in the Northern Region. Their survey of all clinical directors revealed that:

- all were carrying out some allergy work, though none could quantify it;
- 40% had no paediatrician with an interest in allergy;
- 70% had no paediatric allergy dietician; and
- 60% had no nurse with an interest in allergy.

98. Some areas with a paediatrician with an interest in allergy lacked nurse or dietician support; some nurses and dieticians with such an interest worked in areas with no trained paediatrician.<sup>106</sup> Most districts carried out skin prick tests, some performed challenge tests, and most dispensed adrenaline injectors, but with “a hugely varied incidence”.<sup>107</sup> According to Dr Clark and Professor Cant, children with eczema and asthma were well served by respiratory paediatricians and dermatologists, but children with food allergy or recurrent chronic urticaria were very poorly served. Despite the fact that food allergy was by far the commonest reason for people seeking advice, few local hospitals could offer an appropriate range of professional expertise to advise patients on management of the condition, on an appropriate diet or on the use of adrenaline auto-injectors.

99. The RCPCH also commented that many children were currently being treated in adult clinics. This contravenes the tenor of the Department’s National Service Framework for Children, which states that all young people should have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.

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104 Ev 130

105 Ev 123

106 Ev 147

107 Ev 147



100. **Childhood allergy presents problems which are in some respects identical, but in others distinct from those experienced by adults. What is most noticeable is that the gap between need and service performance is wider and growing faster in the case of paediatric allergy. We do not find it acceptable that children are being treated in adult settings and that there are only half a dozen consultant specialists in child allergy, given the prevalence of allergies amongst children.**

101. **We endorse the suggestion of the Royal College of Paediatrics and Child Health and the Royal College of Physicians that there should be a parallel development of paediatric allergy services to those for adults, with the creation of regional centres, each staffed with a minimum of two paediatric allergists and support staff.**

102. Schools have a key role to play in dealing with children who have allergy. We received evidence of some good practice in many schools but also much disturbing evidence, not least in some personal accounts, of ignorance and ineffectiveness in the monitoring and treatment of children. Dr Philip Doré, a consultant immunologist from the Hull and East Yorkshire Trust, cited a survey conducted in October 2003, which showed that, of 280 local schools surveyed (59% response rate):

- 82% had no policy on allergic reactions;
- 55% had no training on dealing with allergic reactions; and
- 67% would like to receive training.<sup>108</sup>

103. The RCP called for community paediatric nurses, working with specialist allergists, to carry out school and nursery visits so as to train staff. We asked witnesses whether school staff were reluctant to become involved in this area of care. David Reading, for the Anaphylaxis Campaign, told us he thought that this problem was diminishing, but that it was crucially important that teachers were properly supported:

First of all, you need the teachers to volunteer ... but you do need somebody, preferably—well essentially—a medical person to go into the school to seek out the volunteers and to train them in the use of injection. I know in good areas like Southampton and parts of London and Cambridge you will get excellent systems set up where people train to go in and train the staff, but this is patchy. Around other parts of the country teachers will understandably be very frightened at being asked to inject an adrenalin pen.<sup>109</sup>

104. There is evidence to suggest that, where a specialist allergy centre does exist, good allergy care in schools follows. In Cambridge, where many children are treated, allergists set up links with the community paediatric teams and this has led to the development of high-quality care in schools. School staff feel confident to deal with allergic emergencies and anxiety amongst patients and children has been reduced. There has been a substantial reduction in further allergic reactions. Gradually all local schools have developed allergy policies and undertaken annual retraining. This system has spread through the region, and led to recommendations for good practice in schools. But these systems need leadership

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108 Ev 108

109 Q24



and ready access to advice from an allergist, lending further support to the desirability of establishing a major centre in each region.<sup>110</sup> Regional allergy centres can extend their services into the community and give parents and staff in playgroups, schools and elsewhere the knowledge and confidence to manage allergy well. They can provide guidance for good practice in the care of children at risk of anaphylaxis in schools.

105. The Anaphylaxis Campaign highlighted the importance of careful management of severe allergy within schools, stating that with communication between parents, staff and medical representatives, and with planning and precautionary measures in place, children with severe allergies should be able to experience school normally.<sup>111</sup> Emphasising the importance of teachers working with parents to agree basic and emergency procedures for children who suffer from anaphylaxis, the Campaign endorsed the use of a protocol, developed by parents and the school, in consultation with the school nurse, the child's treating doctor and the education authority. They suggested this should cover such issues as symptoms, emergency procedures, medication, food management, staff training, precautionary measures and professional indemnity.

106. The Department for Education and Skills encourages all local education authorities and schools to adopt the guidance *Supporting Children with Medical Needs: a good practice guide*,<sup>112</sup> which includes advice on dealing with children with anaphylaxis and suggests the use of protocols for children with severe allergies, although schools are not obliged to develop such policies.

**107. It should be recognised that with a specialist allergy service linked to a community paediatric team, help and support for school staff can be offered and children at risk of anaphylaxis can be managed. The creation of regional, specialist paediatric centres across the country, making expertise available to the schools through community paediatric teams, is the key to giving school staff the confidence that this can be done. This should be implemented as a matter of urgency.**

**108. We recommend that until a regional paediatric service can be established all local education authorities and schools should be guided by the *Supporting Children with Medical Needs: a good practice guide* and Anaphylaxis Campaign guidance. In addition, Strategic Health Authorities should ensure that community paediatricians liaise with the major allergy centres for advice on management of at risk children in schools until they have a consultant paediatric allergist in their region.**

## Provision outside the NHS

109. The lack of provision of specialist allergy treatment in the NHS leads many patients to pursue treatment in the independent sector, either through the use of private sector clinics offering diagnosis and/or treatment, or through the purchase of tests claiming to diagnose allergy and treatments, some of which will be herbal or homoeopathic. Muriel Simmons,

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110 See Vickers et al, "The management of children with potential anaphylactic reaction in the community", *Clinical & Experimental Allergy*, 1997, pp 898–903; Ewan et al, "Long-term prospective observational study of patients with peanut and nut allergy after participation in a management plan", *The Lancet* 2001, 357:111–15.

111 See the Anaphylaxis Campaign's Allergy in Schools website on <http://www.allergyinschools.org.uk/>

112 Available from <http://www.teachernet.gov.uk>

for Allergy UK, told us that people turned in desperation to the independent sector. Her organisation had encountered “more than one case where people have lost their life-savings and have been told to sell their homes”.<sup>113</sup>

110. We received a very large and worrying body of evidence both from health professionals and from patients to suggest that much of the ‘diagnosis’ of allergy conducted outside the NHS, and some of the treatment offered, was ineffective, expensive and in some cases dangerous. While it was widely accepted that in a small number of centres good advice and treatment were available, often provided by staff either working or trained in the NHS, there was a huge amount of unvalidated testing taking place.

111. Given the lack of expertise relating to allergy in the primary care sector it is probably unsurprising that many people feel it worthwhile to have themselves tested in the independent sector. However, most such testing is, in the words of Professor Warner, “of no value whatsoever”.<sup>114</sup> In the view of Dr Philip Doré, independent sector clinics offering alternative medicine “often manufacture illness and rarely treat allergic disease adequately”.<sup>115</sup> For Dr Adrian Morris, a GP with an interest in allergy working both at the BUPA hospital in Farnham, Surrey and as a clinical assistant at the allergy clinic at the Royal Brompton Hospital, the unregulated private allergy sector was a source of great concern:

Allergy sufferers, despondent that they cannot get access to an NHS allergy diagnostic service then approach the unregulated private sector. Often practitioners are not even medically qualified and the testing methods have no scientific basis nor have been validated. These pseudo-diagnostic tests usually designed to identify multiple “sensitivities” included VEGA testing (black box), applied kinesiology (muscle test), hair analysis and the leucocytotoxic tests (marketed as Nutron or ALCAT tests), all of which have been discredited over the years. Unfortunately the plethora of these tests and pseudo-diagnoses is growing at an alarming rate. These practices provide no useful role in allergy diagnosis as they confuse the public about their allergies and put individuals onto unnecessary and sometimes dangerous diets.<sup>116</sup>

112. In 1998, the Consumers’ Association evaluated four different allergy testing services, advertised in magazines, available on the high street, by post or from independent practitioners. They concluded that “none of the tests reliably diagnosed allergies”; in one case, a researcher who was allergic to peanuts was categorically told he was not allergic, by a practitioner of ‘applied kinesiology’, a form of complementary therapy which claims to detect changes in muscle strength so as to provide an insight into underlying causes of health problems. Generally, the tests listed very long lists of foods to be avoided, although these were not based on credible evidence. Nevertheless, exclusion diets based on these lists would have led to people eating very unbalanced diets.<sup>117</sup>

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113 Q64

114 Ev 58

115 Ev 108

116 Ev 160

117 *Health Which?*, December 1998, pp13–15

113. Although the Consumers' Association report is not recent, we received plenty of evidence to suggest that problems still prevailed. Dr Jonathan Hourihane, a paediatrician in the Southampton allergy clinic, described paediatric allergy services as being "plagued by the interventions of practitioners who are not qualified in what could be considered medical allergy".<sup>118</sup> The dangers of such interventions were stark:

I certainly have personal experience of individual children who have had testing by homoeopaths and other practitioners, which have demonstrated the 'safety' of 'safe foods'. These children have gone on to suffer severe allergic reactions on exposure to that 'safe' food. Conventional testing in our clinic with the foods turned out to be positive showing the food to be unsafe.<sup>119</sup>

114. Professor Holgate, for the NASG, told us of his experience as part of an RCP team sent, at the request of the Chief Medical Officer, to visit a private hospital in England that undertook a range of diagnostic and therapeutic procedures:

This hospital had seen 12,000 patients over a period of six years, had used a very wide range of diagnostic and therapeutic procedures, none of which had been validated. Not only that, they were seeing children and there was not a single practitioner there qualified in child health, they were using treatments that had never been properly tested using established procedures and, in fact, the whole activity they were engaged in was very alarming and worrying.<sup>120</sup>

115. Dr Katherine Sloper, a consultant paediatrician at Ealing Hospital NHS Trust, reported that a significant proportion of creams prescribed for eczema from some alternative health workers in London had been shown to contain a high level of corticosteroids. Patients had not been made aware of this, and there were potentially severe long-term side effects.<sup>121</sup>

116. The Department's submission noted that in April 2004, the Healthcare Commission took over responsibility for regulating and inspecting the private and voluntary healthcare sector, which was previously the responsibility of the National Care Standards Commission. The duty to regulate and inspect private and voluntary healthcare is laid out in the Health and Social Care (Community Health and Standards) Act 2003. The Department acknowledged that not all allergy screening services would come under the regulatory arm of the Healthcare Commission, as only those providing medical treatment are registerable. Therefore all those allergy screening centres that screen, but do not treat, are not required to register.<sup>122</sup>

117. Dr Ladyman told us that individuals should have the right to use alternative medicine if that was their wish, but that he was concerned about the lack of evidence for some of the claims made. He used the word "poppycock" to describe the quality of diagnostic tests

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118 Ev 193

119 Ev 193

120 Q112

121 Ev 162

122 Ev 74

being sold through supermarkets, and indicated that he would give careful consideration to any recommendations we might make in the area of regulating diagnostic services.<sup>123</sup>

**118. We are concerned that the current arrangements for inspection of the independent sector by the Healthcare Commission only cover facilities providing medical treatment. Evidence submitted to our inquiry has illustrated that the use of expensive, and often useless tests, creates considerable unnecessary expense and worry for patients and also may place them at risk. We therefore recommend that the Healthcare Commission should be required to inspect organisations providing diagnostic services in allergy, as well as those offering treatment.**

## 3 The capacity of NHS services to meet demand

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### Unmet need?

119. The Department accepted the estimated need for allergy care provided in the RCP Report—15 million people in England with allergy, 10 million likely to need treatment in any year, 3 million needing specialist care. We were interested to know what evidence was available on how well need was being met.

120. In oral evidence the Minister told us he believed there was no good evidence of unmet need:

Do I think that there is clear evidence of unmet need in the system? There I think the evidence is less clear and, in my view, and looking at the waiting list figures and the referrals—given that we can have a debate over whether referral patterns are correct or not—I believe that the NHS has absorbed the increase and coped with it reasonably well ... I think there is 1% [of patients waiting] over 20 weeks for referral to a specialist but those were figures based on figures earlier this year, so even those figures are a lot less now.<sup>124</sup>

121. To support this contention the Department included the following table of waiting times for Immunology and Allergy collated together in their submission.<sup>125</sup>

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123 Qq219–23

124 Q138, 142

125 Waiting Times for 1st Outpatient Appointments (England 4th Quarter 2003/4), Ev 73

| GP WRITTEN REFFERRALS ONLY                                    |       |   |          |          |           |           |             |  |           |
|---|-------|---|----------|----------|-----------|-----------|-------------|--|-----------|
| Number of referral requests for first outpatient appointments |       | Effective length of wait from receipt of GP written referral request to first outpatient attendance (weeks) |          |          |           |           |             | Not yet seen at the end of quarter who have been waiting (weeks) |           |
| GP Written  | Other | 0 to <4   | 4 to <13 | 13 to 17 | 17 to <21 | 21 to <26 | 26 and over | 13 to <17  | 17 to <21 |
| 1,976   | 571   | 352   | 806      | 559      | 73        | 1         | 1           | 37   | -         |

122. Dr Ladyman used these figures to suggest to us that “on the evidence we have the service is coping, is absorbing the increase, people are getting the treatment they need within a reasonable period of time”.<sup>126</sup> However, information on waiting times for immunology and allergy were collated together; the total number of recorded cases appears well below recognised capacity for allergy alone<sup>127</sup> and, crucially, the patient journey through the system in search of appropriate care was not recognised or recorded.

123. When we asked the witnesses from Allergy UK and the Anaphylaxis Campaign to comment on these figures, they told us these did not correspond with their experience.<sup>128</sup> Muriel Simmons, for Allergy UK, disputed them, and David Reading for the Anaphylaxis Campaign pointed out that even quite short waits could be distressing, especially given the fact that much of the burden of disease was borne by children:

If a child does have a severe allergy ... and there is that anxiety ... they are going to find any wait of, say, 12 weeks an absolute nightmare, if a child is believed to be at risk of a fatal reaction. Often the truth is different and manageable, most certainly manageable, but it is only manageable when you have that proper care and proper information and guidance. To wait probably even for more than a month for some of these parents is to them an absolute nightmare. Realistically, the tales we hear are of 11–12 months between the time they first see the GP and when they actually get to see the consultant, and then sometimes there is a wait to get the test results back, so it can be many, many months.<sup>129</sup>

124. The sheer volume of inquiries received by the allergy charities suggests to us that the NHS is not meeting the needs of patients with allergy. The Anaphylaxis Campaign receives 16–20,000 enquiries annually via a telephone helpline, mail or email. The commonest problem they encounter is that patients feel there is a lack of information or understanding of their condition in the NHS. Many of the 140,000 leaflets it sends out each year are to health and education professionals. The Campaign’s website records around 4,000 hits per day. Allergy UK reported even more activity. It received around 60,000 requests for assistance in the last year, and the number of people seeking advice had grown on average by 21% in each of the last three years.<sup>130</sup>

126 Q213

127 Q102 Professor Andrew Wardlaw), Q175

128 Qq52–54

129 Q54

130 Ev 3; Ev 1

125. A strong counter-argument to the case that the Minister made—that lack of pressure within the service suggested that the NHS was coping well with the increase in numbers—came in the evidence from the BSACI. They suggested that rates of referrals for allergy services in areas where there is an inadequate service (which was most places) were not a good guide to patient demand for services for the following reasons:

- The skill level in primary care will be lowest in areas where there is a paucity of secondary care services. This means that the GP may not be aware that a specialist opinion could benefit their patient and, even if they did recognise this, there would be no one to refer them to.
- The capacity for seeing new patients is so low that allergy practitioners limit their practice by not advertising the service or by limiting the types of patients seen to the specialist area in which they practise so that a comprehensive service is not provided even though an allergy clinic is stated as being present.
- Hospital managers under pressure from waiting list targets discourage practitioners from taking on more new referrals than they can see in the time available. In extreme situations this approach can involve closure of the service. Several clinics have closed or cut services in recent years including those in Reading, the Isle of Wight and Liverpool, where full-time allergists who retired were not replaced.<sup>131</sup>

126. The BSACI argued that where a proper service and good local capacity were available, new patient referrals were approximately what one would expect from the estimated patient population with severe allergy:

For example, in Leicestershire (population one million) 2,000 new patient referrals are made a year with a current waiting time of 13 weeks. In contrast, a single part-time allergy clinic such as the one that serves the South West (population five million) would have a capacity of approximately 250 new patients a year and yet have a similar waiting time. Referral rates and waiting times for new patient appointment do not therefore relate to need but to the level of service provided. A clear example of this is the allergy service in Cambridge which had approximately 500 referrals in 1993 and 5,000 in 2003. This 10-fold increase was due almost entirely to increased awareness of the service by local GPs.<sup>132</sup>

127. Many of these points were buttressed by a wide range of the evidence we received. Our analysis of memoranda from allergy sufferers, annexed to this report, suggests much longer waiting times than those contained in the Department's data. It seems likely that when an allergy patient is referred to a specialist who is not an allergist, and is then referred on, each step in the chain may be within the stipulated Government maximum waiting time, but the total waiting time the patient experiences before receiving effective treatment will be unduly extended. For example, 'Mrs Longworth', a 60-year-old patient in the Addenbrooke's survey, waited in total one year to see the right consultant, having been

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131 Ev 52

132 Ev 53



inappropriately referred in the first place, despite having suffered near fatal anaphylaxis with cardiac arrest following an allergic reaction to drugs used in general anaesthesia.<sup>133</sup>

128. Support for the BSACI view that, where good specialist services were available, local demand was great, came from many memoranda. Dr Jonathan Hourihane, a consultant at Southampton, suggested that, while some referrals came from as far as Wales, Scotland or Sheffield, two-thirds were from the local region and contiguous PCTs traditionally associated with Southampton. He concluded: “This suggests that in Southampton, as in other areas of the United Kingdom that have allergy services, if you build such a service, the local health economy will send their patients to it.”<sup>134</sup> Two consultants at Southampton presented disturbing evidence that the Trust’s directorate had actively discouraged them from introducing the new national code to record allergy treatment. Dr Hourihane, supported by Professor Warner, told us that on their attempting to introduce the code for services an email had been sent from the Directorate on 26 May 2004 asking them not to introduce the code since “this will automatically send the message that we are delivering a fully supportive service. If we are to develop this, it must be done in the correct manner as a concept paper and a business case, for which there is currently no financial resource available”.<sup>135</sup> It should be noted, however, that the Minister regarded this evidence as “unfair”. He maintained that an email was generally understood to be an “informal communication” and that Professor Warner should have initiated a “formal exchange of letters” if he disagreed with the policy.<sup>136</sup>

129. Dr Gideon Lack, a consultant in paediatric allergy and immunology, told us that waiting lists rapidly grew in his trust, St Mary’s, London, following the build up of three paediatric allergy clinics. But with the waiting list for new appointments exceeding 12 months and with NHS targets becoming a pressure on the Trust it became imperative to bring these down:

This was done through a series of allergy drives where extra clinics were set up to see more allergy patients. This temporarily decreased the waiting list but each time it climbed back up again. Given that many of our patients were highly complex and required follow-up appointments our follow-up waiting list is up to one year. This is completely unacceptable. Finally we have been forced to only accept GP referrals locally. If a GP from out of area refers to us an appropriate patient with complex allergies we cannot see that patient unless that patient is referred to us through a paediatrician. This creates a further unnecessary additional burden on the NHS in other areas.<sup>137</sup>

130. We note that no reference was made in the Minister’s oral evidence to the estimates of need in relation to demand submitted by the NASG (and sent earlier to the Minister). With whatever caveats about the assumptions which had to be made in the absence of hard information, these estimates are a direct attempt to measure a service gap; and they indicate one of worrying size. If provision in the hospital sector can only deal with about

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133 Ev 33 (Dr Shuaib Nasser)

134 Ev 192

135 Ev 192; Q82

136 Q196

137 Ev 125



2% of the estimated need, there can be no doubt the service gap, and consequently the inadequacy of patient care, is substantial.

131. A final major problem with the Minister's assertion that Government waiting lists do not support the suggestions of unmet demand lies in serious flaws in the data on which they are based, flaws which the Minister himself acknowledged.

**John Austin:** Our witnesses specifically challenged the Department's figures on waiting times and argued that the figures produced are not credible because they largely relate to immunology as well as allergy.

**Dr Ladyman:** Yes, exactly.

**John Austin:** Also because many of the allergy sufferers are not in there because they are on other waiting lists.

**Dr Ladyman:** Yes, and I have acknowledged that and accept that.

**John Austin:** You accept that they are fairly meaningless in that sense to assess the extent of allergy?

**Dr Ladyman:** I accept that many people being referred for allergies will be being referred, for example, to dermatologists, dieticians or to other people ...<sup>138</sup>

132. We asked the Minister whether it would not be sensible to obtain separate figures for allergy and immunology. He told us that this was something the Department would "reflect on" though he thought it was important to bear in mind that any additional data gathering might impose an additional bureaucratic burden on services.<sup>139</sup>

133. The Department did in fact issue a national allergy code to be used for recording the amount of allergy work being carried out within the NHS on 1 April 2004. This is an important step to proper measurement of services being provided and of any service/needs gap. The Minister appeared to be unaware of the introduction of the Code.<sup>140</sup> If the Code is not implemented effectively it will fail to be a valid and useful measure. Once the Code is implemented it will give a measure of work undertaken by specialist allergists. It will, however, remain difficult to measure allergy work undertaken in clinics run by consultants in non-allergy specialties, the majority of current provision for allergies, as this will not be appropriately coded.

**134. We recommend that the Department should ensure that the National Code to record allergy services is implemented comprehensively and effectively and that, as the NHS moves allergy care more towards its mainstream, there should be an adequate investment in clinical and operational research into allergy, so that understanding can grow across the service about what this area of care can offer. It is vital that the Department obtains an accurate map of where allergy services are actually being**

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138 Qq151-53

139 Q154

140 Q194

provided so that it can more effectively secure equitable provision, and more realistically gauge current demand on services.

135. Overall, we do not accept Dr Ladyman’s thesis that the apparent lack of excessive demand for services indicates that there is no convincing evidence of unmet need. It is not possible for doctors to refer patients to services where none are available. Further, there is no mechanism to measure this unmet need. Patients themselves will often not be aware of specialist services and are often in any case not properly diagnosed. The accounts we have received from hundreds of patients demonstrate the frustration felt by individuals over the difficulties in securing *appropriate* treatment, and over the lengthy waits and long journeys they are experiencing. The NHS is currently not a national service as far as allergy care is concerned. And even when there is an allergy clinic within reasonable travelling distance, the expressed opinion of the Department appears to be that patients for the most part should be seen elsewhere before a select few are referred on to an allergy specialist. Passing individuals around the system in a way driven by the scarcity of appropriate care is not right. And indeed, as we have noted above, for patients in many parts of the country even being passed on is not a viable possibility without excessively long journey times. It is clear to us that there is a large and growing gap between need and appropriate allergy care within the NHS.

### Commissioning and funding of services

136. Much of the evidence we received from health professionals involved in the treatment of patients with allergy related to the ways in which services were funded. A source of concern to a number of our witnesses was the extent to which specialist services for allergy were funded as research institutes, out of budgets for university research, rather than by the NHS. Stephen Durham, Professor of Allergy and Respiratory Medicine at the Royal Brompton and Harefield Trust, told us that only two-elevenths of his post was funded by the NHS. The service he provided was largely supported by clinical research fellows and a specialist research nurse, a situation he described as “clearly unsatisfactory”.<sup>141</sup> Professor Warner suggested that if Southampton University’s research agenda was to change, the specialist service he offered could “disappear overnight”.<sup>142</sup> He told us:

I am the professor of child health (Southampton), so I am responsible for all paediatrics, not just for allergy immunology. There is no guarantee when I retire that I will be replaced by someone with an interest in allergy immunology; it could be an endocrinologist or a cardiologist.<sup>143</sup>

137. Professor Holgate, for the NASG, noted that 80% of the full-time allergy practitioners were paid for from academic and research salaries and that “they are using their research time to deliver a clinical service”, something which he thought was “unacceptable”.<sup>144</sup>

138. The Minister recorded his surprise at the suggestion that this was unsatisfactory. His view was that allergy treatment relied heavily on leading-edge scientific research, and that it

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141 Ev 106

142 Ev 57

143 Q76

144 Q72

was thus entirely appropriate that specialists had close connections with research institutions, in a “marriage between the leading research and clinical practice”.<sup>145</sup> Addressing the concerns raised by Professor Holgate, the Minister rejected the “unspoken implication” that a service would disappear from an area if a particular university chose to alter its research agenda. Instead, he argued:

It would be the responsibility of the local Primary Care Trusts working within the framework of the Strategic Health Authority in that area then to say “If that is not going to be there in the future we need to find another service and commission services, so we will recruit another allergy specialist and we will set up another service to replace that.”<sup>146</sup>

139. Clear evidence to contradict the Minister’s contention that, if an individual specialist service closed down another would be commissioned by PCTs to take its place if there was local demand, came in the submission from Dr Rita Brown. She had run a specialist clinic in the Royal Berkshire Hospital, Reading. This closed down in the year 2000 when she retired, even though it had been seeing over 1,000 patients a year, and had a 12-month waiting list.<sup>147</sup> The consequence was that there was no longer any local provider and patients had to travel long distances to receive treatment. Other evidence we received indicated that the closure of the Reading clinic had boosted the pressure of numbers to attend the clinic in Southampton.<sup>148</sup>

140. Kate Hopkinson and Dr Richard Powell, from the Queen’s Medical Centre, Nottingham, reported that their clinic, which had a consultant and two nurse specialists, had received over 60 new allergy referrals a month. The team had been struggling to keep patient waiting times down to an acceptable level. However, a recent application to local PCTs to maintain the service had failed to secure funding and “recommendations were returned to dissolve the allergy service currently provided”.<sup>149</sup>

141. Even where specialist commissioners determine there is a need for services, funding does not automatically follow. Professor Adnan Custovic and Dr Andrew Bentley of the North West Lung Centre at the Wythenshawe Hospital, Manchester, told us that the North West Regional Commissioning Group had decided in 2001 to review the current provision of allergy services with a view to determining future provision. This found that:

- There was no regional allergy service and most patients were not being appropriately identified and treated;
- There was little or no provision for primary care allergy testing in the community and no community care for people with allergy;
- There was no full-time allergist-led NHS service provided in the North West;

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145 Q138

146 Q143

147 Ev 158

148 Ev 152 (Professor Anthony J Frew)

149 Ev 132

- The provision of services in the North West was inadequate as evidenced by the long waiting times of patients referred to the patchy service that did exist;
- Most patients with allergic disease in the North West never saw an allergist; and
- Patients and GPs had difficulty in accessing the currently available services and, as a result, desperate patients sought help from non-validated sources.<sup>150</sup>

142. The Specialist Commissioning Group therefore concluded that there was a need to develop a service, and put forward a proposal for setting one up in January 2003. But, to date, “it has proved impossible to persuade local commissioners to provide financial support for the development of the service”.<sup>151</sup>

143. Professor Wardlaw, for the BSACI, felt that the current commissioning arrangements were not working well, and that the general ignorance of allergy amongst commissioners underlay the neglect in the provision of services. The NASG had demonstrated the lack of priority accorded to allergy by commissioners by contacting those responsible for commissioning:

We were given the names by the Department of Health of the 30 PCT leads who are responsible for allergy commissioning and we wrote to all of them some time ago and of the 30 only seven replied, and of those seven, allergy was not a priority for any of them.<sup>152</sup>

144. Even when an allergy service of some kind is available locally (either research funded, or receiving no specific allergy-directed support), local commissioners seem all too often unaware of its existence. Dr Katherine Sloper, a consultant general paediatrician at Ealing Hospital NHS Trust, who runs an allergy clinic, noted:

The Ealing PCT Commissioning Department was not aware of the unmet or increasing needs for patients locally who have serious allergies. They are now interested in exploring with me how the community and hospital can support each other in developing allergy services, and we will be meeting together to look at these services. The Ealing PCT Commissioning Department has not identified the need for allergy services apart from recognising that some patients were seen in the allergy clinic at St Mary’s Hospital. They did not know that there was a local Paediatric Allergy Department. They do not fund any local adult service, and I know from the experience of patients who have asked me about it, that adults have not been able to have any specialist advice.<sup>153</sup>

145. The view of several of those submitting evidence to us was that allergy does not register anywhere in local plans for a majority of commissioners who were more concerned with areas where national targets and priorities had been set. Professor Wardlaw, for the BSACI, articulated this view:

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150 Ev 94

151 Ev 94

152 Q86

153 Ev 162

We have the Department of Health targets with the Cancer Plan and the emphasis on cardiovascular sciences. So what you tend to get is you have a pot of money and there is a lot of horse-trading going on, a lot of emphasis on waiting list targets and that sort of thing ... you need strong champions locally to try to press for service development, and again allergy has suffered because there are not any local champions.<sup>154</sup>

146. Dr Ladyman informed us that PCTs were currently developing their Local Delivery Plans for the commissioning of services. He recognised that there was “not the genuine recognition of the needs of allergy sufferers when the last round of Local Delivery Plans were written” but said he “would be very surprised if Primary Care Trusts around the country this summer, when they start sitting down to write their Local Delivery Plans, were not thinking, ‘We need to do a bit better for allergy.’”<sup>155</sup> Our evidence makes us far from sanguine that this will be the case. And we find the degree of understatement on the part of the Minister rather alarming. Government policy places the commissioning process as a main driver for change in the NHS. Failure by the commissioners to notice an epidemic on the scale of allergy currently, even when it is being misclassified as other illness (indeed, exactly when it is being so misclassified), suggests that the system is failing allergy sufferers.

147. Difficulties in stimulating local budget holding commissioners were discussed at a meeting between Jon Cruddas MP and the Minister in January 2004.<sup>156</sup> At that time the Minister promised to ask the Chief Medical Officer whether he would be prepared to oversee the development of an “action plan” to guide and support local allergy commissioning. We are not aware of the outcome of the discussions between the Minister and his Chief Medical Officer; but we believe that the development of such a plan would be a helpful step forward.

148. Additionally, more targeted commissioning mechanisms are already available in the NHS. One way to promote change through commissioning, albeit one which would face a number of difficulties, would be for the required regional allergy centres to be commissioned through the specialist commissioning process. Such services are defined by the Department as those that have low patient numbers, and are generally high-cost, requiring a certain critical mass of patients to make treatment cost-effective.<sup>157</sup> The Specialised Service National Definition Set includes 36 such services, one of which is allergy services relating in particular to severe allergic disease and anaphylaxis.<sup>158</sup> Due to the high-cost, low-volume nature of these specialised services, the Department recommends that services within the Definition Set are planned and commissioned for larger areas and populations than is normally the case. For regularly used hospital services, one PCT will normally work with local acute trusts to plan services for the residents of the geographical area for which they are responsible, which are normally coterminous with local authority boundaries. Specialised services are commissioned by regional groups of PCTs for their combined populations (normally over one million people) often with one lead PCT acting

154 Q80

155 Q190

156 Ev 45 (NASG/BSACI)

157 Specialised Services definition available from <http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SpecialisedServicesDefinition/fs/en>

158 Specialised Services National Definitions Set (2nd Edition) Definition 17

on behalf of the others. All PCTs contribute towards the cost of specialist treatment for their pooled area, and therefore some of the financial risk associated with very high-cost unpredictable treatment is spread between the consortium. No additional funding exists for specialised services; funds must be allocated from PCTs' normal budgets, which are based upon the size of their local population. Besides the allocated funds, extra financial resources are often required. Spending on specialised services is currently estimated to be around 10% of PCTs' budgets, or around £4 billion every year.

149. The Manchester case described above, and others, such as Addenbrooke's, where bids for local specialist commissioning failed,<sup>159</sup> or Southampton, illustrate the difficulties in making this process work to establish regional allergy centres covering populations of 6–8 million. There is little or no perception of a problem of unmet need among the local budget holders. And quite a large number of them would need to change their minds, agree to work together and pool resources, to get something off the ground. In reality, there are insurmountable difficulties facing this route to change. The difficulties are structural (the large numbers who would need to combine to provide regional level funding for the key resource/regional centre). They are managerial, with no data on the actual scale of allergy treatment and little incentive to give priority to this area in the face of competing demands. But above all they are caused by a lack of perception that there is a problem and an absence of local leadership. Local champions and clinical leadership are needed to achieve this prerequisite of change.

150. One potentially helpful development is that set prices for allergy services have, from 2004–05, been included in the national tariffs or Health Resource Groups (HRGs) supporting the new Payment by Results system.<sup>160</sup> HRGs should ensure that valid prices for allergy treatment are harmonised across the NHS, enabling PCTs to plan the use of their budgets better in future.

151. The introduction of a national allergy tariff and the allergy code are important steps, as they mean allergy can now be registered in NHS systems. It is clearly necessary to ensure that tariffs are appropriately priced, implemented uniformly across the NHS, and do not introduce financial incentives for particular patterns of referral. The tariff must follow the GP's decision on the patient and not determine where the patient can go.

152. A further, and possibly more direct route to achieve change is through the National Specialist Commissioning Advisory Group (NSCAG), a centralised Departmental body that intervenes in local commissioning arrangements in special circumstances, identifying, funding and contracting specialised services centrally, advising the Secretary of State on commissioner guidelines, and funding the cost of new developments. NSCAG generally becomes involved in the commissioning of services that it has defined as 'Supra Regional' or where there is an overriding economic or clinical justification for national contracting, or where something has gone wrong, or where there is a previously unrecognised need to do something, and to do it quickly. Supra Regional services are those that are very specialised, and are therefore required to be provided in a small number of centres, planned and run on a national basis.

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159 Ev 151 (Mr Malcolm Stamp)

160 Allergy HRG information available at [www.dh.gov.uk](http://www.dh.gov.uk) under "Publications, Policy and Guidance".



153. Some 32 services are currently designated as ‘highly specialist’ or ‘national’. New services are considered every year. To be considered, a service fitting the NSCAG criteria must:

... be facing insurmountable problems for which the only workable solution is thought to be designation and central funding. In addition, the application should provide detailed evidence of the reasons why the existing funding mechanisms are unable to accommodate the service and the anticipated consequences if the application is not successful.<sup>161</sup>

154. Additional budgets required to finance newly designated services come from NHS growth money for new services or from levies on all PCTs to cover the costs up to the level of a service already funded within the NHS. If the Department is prepared to recognise the problem and act on it, a mechanism exists to initiate the work on the creation of the specialist centres.

**155. Given the serious inequality of access to specialist allergy services, the key role which regional centres would play in turning matters around and the absence of active allergy commissioning locally across the NHS, we believe that there would be merit in the National Specialist Commissioning Advisory Group treating the specialist allergy services as national services, and thus eligible for specific NHS funding. To do this would be to take a first step in the proactive commissioning of allergy services.**

156. We further believe that the underlying problem of how to stimulate and inform local PCT commissioners needs also to be addressed. Fortunately, the Minister has already suggested a way forward to begin to do this. We welcome the Minister’s suggestion that he should ask the Chief Medical Officer to prepare an action plan and we look forward to its publication which we hope will take account of the conclusions of our report.

## 4 Levers for change: creating an effective allergy service

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157. A recurrent theme in the evidence we received was the lack of resources currently available for allergy in the NHS and the pessimistic outlook for the allocation of planned additional resources in the future. We have addressed the managerial aspects above. In clinical terms, fewer than 30 specialist doctors and six paediatric allergists are the total expert resource available. We have concluded that an expansion in allergy training would not only create a cadre of specialist doctors, it would also be the first step in the development of a new service. This would underpin and enable developments in all levels of NHS service provision and thus have a multiplier effect.

158. We were therefore very concerned to discover that in recent workforce reviews, the very modest recommendations for additional allergy trainees by the Department’s own

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<sup>161</sup> Health Service Circular 1999/132



expert advisers (the Workforce Review Team's advice to the Workforce Numbers Advisory Board) have not been accepted. For example in 2003, where the recommendation was for seven additional posts, the allocation was zero (later one post was allocated after appeal). More recent advice from the Department's workforce advisers has been informed by the RCP analysis of the scale of the allergy epidemic, and for 2005–06 and 2006–07, 10 additional training posts for adult allergists were thought to be needed each year, with a similar number for paediatric allergy. However, only one post has been allocated, and this has been mortgaged against future years' funding. This means that further posts are unlikely to be forthcoming for several years. Such an allocation is not even enough to maintain the existing vestigial consultant workforce, which will soon begin to decline in size as consultants in post retire.<sup>162</sup>

159. The decision on numbers of trainees and central funding is in the control of the Department and is a core strategic responsibility. It is commonly agreed throughout the NHS that unless central funds are provided, local health authorities will not be able to commit to the basic training of doctors outside the ring-fenced, established, national clinical priority areas. As a gesture, the Department has suggested that training posts might be created through local initiatives. But for a currently vestigial specialty such as allergy, this seems to us to be pointless—particularly so when, to develop the human resources required by specialist centres, as many as 24 local PCTs would need to club together to fund the required training in each regional case. We received no evidence to suggest that in the current circumstances this is a realistic prospect for the country's PCTs.

160. We were told of promises given by the Minister to the NASG in January 2004 to look at numbers of funded training posts being made available for allergy. We are not aware of any conclusions reached to date.<sup>163</sup>

161. The Department has been advised by its own expert committee that the number of doctors able to specialise in allergy care within the NHS is about to decline due to natural wastage. A small increase in training provision of two additional posts is required even to maintain the workforce status quo. And the most recent advice to the Department has gone beyond the preservation of current levels.

**162. We are strongly of the view that the Department should use its ability to invest in the training of specialist allergy doctors in order to initiate the changes required to bring about a modern allergy service within the NHS. This is the key step in making progress. It is a clear national responsibility to ensure that the NHS has an adequate medical workforce. Investment through the strengthening of the workforce is an economic and cost-effective way of moving towards a national service for allergy.**

**163. The Department has been advised what would be needed both to maintain the existing specialist workforce numbers and to take the first steps towards creating the basis of a national service. Training provision for adult allergy should be increased with an additional 10 posts in 2005 and a further 10 in 2006. A similar number of trainees is needed in paediatric allergy. We believe this would be appropriate and we make this the cornerstone of our proposals for responding to the allergy epidemic.**

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162 Ev 40 (NASG/BSACI); Q72

163 Ev 45 (NASG/BSACI)

164. We also recommend a parallel initiative to develop the slightly different training arrangements for paediatric allergy to bring it up to a state of readiness comparable with that of adult care. Ten paediatric training posts should be earmarked for allergy for 2005 and a further 10 for 2008. In addition, in paediatrics, training in allergy is currently combined with training in immunology and infectious diseases. It is our view that allergy should be a separate disease sub-specialty in the paediatric training curriculum.

165. In developing a service, it is important for young doctors to be able to see a career structure or they will not enter it as trainees. The Department needs to make a commitment to ensure this is clear to commissioners, trusts and individual young doctors, and funding must be set aside for consultant posts in the new regional centres for the trainees to move into. We have identified the NSCAG process as one possible mechanism for achieving this end. But we believe, having noted the success in stimulating and modernising NHS cancer services, that there may be a number of mechanisms available to the Department for achieving the desired ends—if the ends are desired.

166. As part of the commitment to develop regional allergy centres as the first crucial step towards a national NHS allergy service, the Department should endorse and underwrite the creation of additional consultant allergists posts (at least two adult and two paediatric) in every region (as defined in paragraph 85) into which these trainees could move.

167. In total this would amount to an investment by the Department of 20 new allergist doctors beginning in 2005 and a further 20 in 2006–08, covering both adult and paediatric allergy care. This level of investment in training could, we believe, be absorbed within the existing training infrastructure for allergy doctors. Subsequent investment in the future through the employment of these doctors needs also to be assured. We call on the Department to use the means at its disposal to do this.

168. Such an investment plan would help to create the new service infrastructure that we believe is needed. The prescription for change along these lines was given to the Department over a year ago in the RCP report *Allergy: the unmet need*. It is very similar to the approach already in existence in cancer care, where the creation of a network of specialist services on a hub and spoke model has already yielded great benefits.

169. Overall we believe a long-term commitment by the Department to build a modern national allergy service would be the appropriate response to the current situation. Achieving this aim is clearly a long-term endeavour starting from the current very low base of provision. But the problems are not going to go away; indeed, they will increase, given trends in disease prevalence. So we believe a start must be made now. It is important not to fragment the use of scarce resources, so we believe leadership around an integrated strategy is vital, and call on the Department to produce a strategy statement indicating how it proposes to develop allergy services, taking account of all the proposals in the RCP document, as well as those contained in our report. The first essential element needs to be the creation of regional specialist centres to lead and to underpin service development across the whole country and to secure the resources for these in ways that will give everybody confidence in their continued existence in the NHS. But change needs to go beyond this. It needs to be sustainable within the

devolved processes for the modern service. It may be that, as happened with cancer services, an individual, or small group of individuals, could be assigned a specific role to drive through policy change, and provide the millions of allergy sufferers with the appropriate provision for their condition, a provision which is currently largely absent from the NHS. We would like to see proposals from the Department which will bring allergy services into the mainstream of NHS care and a mechanism to ensure their implementation.

## Conclusions and recommendations

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1. We believe that primary care should be the frontline provider of allergy care, but the skill base from which to build an adequate primary care service is lacking. In order to develop an appropriate primary care service, an infrastructure of specialist allergy services is therefore first required. As we propose below, it is imperative that specialist clinics for the treatment of allergy should be developed across the country, so that these can become centres of local networks of competent practice in allergy care, and facilitate the training and professional development of staff in primary care. It will, however, take several years for these centres to be fully operational. So we recommend below a number of measures intended to have a more immediate effect on the capacity of primary care to deal with the growing problem of allergy in the population. (Paragraph 49)
2. We believe a national primary care allergy network should be created to support those working in primary care to allow them to access second opinions, to offer peer review of services and to provide ongoing education and professional development. The active involvement of current and developing specialist centres is crucial to the existence of such a network. We recommend that the Department takes steps to draw to the attention of GPs the directory of allergy services produced by the British Society for Allergy and Clinical Immunology. (Paragraph 50)
3. We recommend that in its next review of the clinical incentives in the current GP contract, the Department should introduce clinical quality markers for allergy. (Paragraph 51)
4. Primary Care Trusts should consider how to ensure that people with allergy in their area know who is appropriately trained and who is clinically accountable for providing a service. We recommend that a named person in each PCT should be identified. This process should be overseen by Strategic Health Authorities as a regional overview will be important. (Paragraph 52)
5. We recommend that the basic training curriculum for GPs should be reviewed, and modified as required, to take account of the need to have allergy as a basic component in the initial training for general practice. (Paragraph 53)
6. We recommend that the Department should disseminate information to all PCTs on training provision in their area. Given the general level of ignorance of allergy in primary care we recommend the Department should provide some financial support to provide access to initial in-service training for a wide range of health professionals. We recommend that the Department assesses the quality of the various training courses on offer to GPs. (Paragraph 55)
7. We conclude that, while GPs with Special Interest could make an important contribution to service development in allergy care, a precondition of their successful

introduction is the prior availability of specialist care to underpin standards and provide clinical training and case management guidance. Nevertheless, the curriculum for GPwSIs could be developed with allergy consultants now, and we recommend that this should be done. The pace of change can then be set taking account of the overall programme required to modernise allergy care within the NHS. (Paragraph 62)

8. We recommend that the GPwSI National Development Team begin work on a framework for GPwSIs in allergy services, working with the current specialist allergy centres (and with additional regional centres once these are established) to identify the core activities of an allergy GPwSI, and the qualifications and/or experience that would make a GP eligible for such a position. (Paragraph 63)
9. To show that it is genuinely committed to this planning phase, the Department should indicate that it wishes to see (and is prepared to finance) the creation of a first generation of GPwSIs in allergy on a sufficient scale to ensure there is a GP with a special allergy interest in each PCT, once sufficient consultants in allergy are available to train them. (Paragraph 64)
10. It seems to us to be manifestly inequitable that there is no comprehensive allergy service in England north of Manchester or west of Bournemouth. The current provision in fact owes nothing to the geographical spread of allergy in the population. Rather, it comprises those centres where specialist research in allergy has taken place, on the back of which clinical services have developed ad hoc. (Paragraph 84)
11. We endorse the proposal of the Royal College of Physicians that a minimum of one specialist allergy centre should be established in areas equivalent to each of the former NHS regions, serving populations of five to seven million, to offer at least some local expertise for allergy sufferers. More provision may well be needed in less densely populated areas. We also endorse their recommendations for staffing levels both for adult and paediatric care, that is to say that each centre should have as a minimum two adult allergy consultants, two paediatric allergy consultants supported by paediatric nurse specialists, two full-time nurse specialists, one half-time adult paediatrician and one half-time paediatric dietician. This is our key recommendation and the one on which all other elements to develop a national allergy service within the NHS will depend. (Paragraph 85)
12. The specialist allergy clinics, other clinics capable of providing allergy services and hospital trusts need to develop new ways of working, or adapt old ways, to provide for a national network of interim care while a new cohort of allergists who will run these new centres is trained. Through these networks, the information could be gathered to locate new consultant allergist posts where unmet need is greatest as new doctors emerge from training. We believe that Strategic Health Authorities should play their part in co-ordinating such activity. (Paragraph 86)
13. In the longer term, we would like to see allergy provided with a full specialist consultant workforce. The Royal College of Physicians' medical workforce projections indicate this would eventually require the creation of around 520

consultant allergist posts. This is clearly an ambitious goal and unachievable even in the medium term when starting from such a low base, even if the resources were available. We recommend that an important more intermediate target would be for most major teaching hospitals to have a consultant allergist-led service, covering adult and paediatric allergy, with appropriate support staff. (Paragraph 87)

14. Childhood allergy presents problems which are in some respects identical, but in others distinct from those experienced by adults. What is most noticeable is that the gap between need and service performance is wider and growing faster in the case of paediatric allergy. We do not find it acceptable that children are being treated in adult settings and that there are only half a dozen consultant specialists in child allergy, given the prevalence of allergies amongst children. (Paragraph 100)
15. We endorse the suggestion of the Royal College of Paediatrics and Child Health and the Royal College of Physicians that there should be a parallel development of paediatric allergy services to those for adults, with the creation of regional centres, each staffed with a minimum of two paediatric allergists and support staff. (Paragraph 101)
16. It should be recognised that with a specialist allergy service linked to a community paediatric team, help and support for school staff can be offered and children at risk of anaphylaxis can be managed. The creation of regional, specialist paediatric centres across the country, making expertise available to the schools through community paediatric teams, is the key to giving school staff the confidence that this can be done. This should be implemented as a matter of urgency. (Paragraph 107)
17. We recommend that until a regional paediatric service can be established all local education authorities and schools should be guided by the *Supporting Children with Medical Needs: a good practice guide* and Anaphylaxis Campaign guidance. In addition, Strategic Health Authorities should ensure that community paediatricians liaise with the major allergy centres for advice on management of at risk children in schools until they have a consultant paediatric allergist in their region. (Paragraph 108)
18. We are concerned that the current arrangements for inspection of the independent sector by the Healthcare Commission only cover facilities providing medical treatment. Evidence submitted to our inquiry has illustrated that the use of expensive, and often useless tests, creates considerable unnecessary expense and worry for patients and also may place them at risk. We therefore recommend that the Healthcare Commission should be required to inspect organisations providing diagnostic services in allergy, as well as those offering treatment. (Paragraph 118)
19. We recommend that the Department should ensure that the National Code to record allergy services is implemented comprehensively and effectively and that, as the NHS moves allergy care more towards its mainstream, there should be an adequate investment in clinical and operational research into allergy, so that understanding can grow across the service about what this area of care can offer. It is vital that the Department obtains an accurate map of where allergy services are actually being



provided so that it can more effectively secure equitable provision, and more realistically gauge current demand on services. (Paragraph 134)

20. Overall, we do not accept Dr Ladyman's thesis that the apparent lack of excessive demand for services indicates that there is no convincing evidence of unmet need. It is not possible for doctors to refer patients to services where none are available. Further, there is no mechanism to measure this unmet need. Patients themselves will often not be aware of specialist services and are often in any case not properly diagnosed. The accounts we have received from hundreds of patients demonstrate the frustration felt by individuals over the difficulties in securing *appropriate* treatment, and over the lengthy waits and long journeys they are experiencing. The NHS is currently not a national service as far as allergy care is concerned. And even when there is an allergy clinic within reasonable travelling distance, the expressed opinion of the Department appears to be that patients for the most part should be seen elsewhere before a select few are referred on to an allergy specialist. Passing individuals around the system in a way driven by the scarcity of appropriate care is not right. And indeed, as we have noted above, for patients in many parts of the country even being passed on is not a viable possibility without excessively long journey times. It is clear to us that there is a large and growing gap between need and appropriate allergy care within the NHS. (Paragraph 135)
21. Given the serious inequality of access to specialist allergy services, the key role which regional centres would play in turning matters around and the absence of active allergy commissioning locally across the NHS, we believe that there would be merit in the National Specialist Commissioning Advisory Group treating the specialist allergy services as national services, and thus eligible for specific NHS funding. To do this would be to take a first step in the proactive commissioning of allergy services. (Paragraph 155)
22. We further believe that the underlying problem of how to stimulate and inform local PCT commissioners needs also to be addressed. Fortunately, the Minister has already suggested a way forward to begin to do this. We welcome the Minister's suggestion that he should ask the Chief Medical Officer to prepare an action plan and we look forward to its publication which we hope will take account of the conclusions of our report. (Paragraph 156)
23. We are strongly of the view that the Department should use its ability to invest in the training of specialist allergy doctors in order to initiate the changes required to bring about a modern allergy service within the NHS. This is the key step in making progress. It is a clear national responsibility to ensure that the NHS has an adequate medical workforce. Investment through the strengthening of the workforce is an economic and cost-effective way of moving towards a national service for allergy. (Paragraph 162)
24. The Department has been advised what would be needed both to maintain the existing specialist workforce numbers and to take the first steps towards creating the basis of a national service. Training provision for adult allergy should be increased with an additional 10 posts in 2005 and a further 10 in 2006. A similar number of trainees is needed in paediatric allergy. We believe this would be appropriate and we



make this the cornerstone of our proposals for responding to the allergy epidemic. (Paragraph 163)

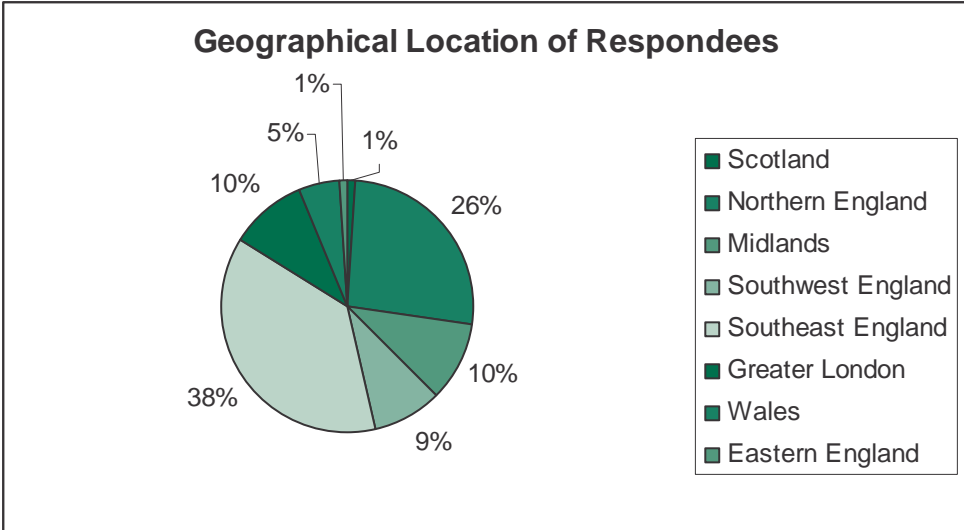
25. We also recommend a parallel initiative to develop the slightly different training arrangements for paediatric allergy to bring it up to a state of readiness comparable with that of adult care. Ten paediatric training posts should be earmarked for allergy for 2005 and a further 10 for 2008. In addition, in paediatrics, training in allergy is currently combined with training in immunology and infectious diseases. It is our view that allergy should be a separate disease sub-specialty in the paediatric training curriculum. (Paragraph 164)
26. As part of the commitment to develop regional allergy centres as the first crucial step towards a national NHS allergy service, the Department should endorse and underwrite the creation of additional consultant allergists posts (at least two adult and two paediatric) in every region (as defined in paragraph 85) into which these trainees could move. (Paragraph 166)
27. In total this would amount to an investment by the Department of 20 new allergist doctors beginning in 2005 and a further 20 in 2006–08, covering both adult and paediatric allergy care. This level of investment in training could, we believe, be absorbed within the existing training infrastructure for allergy doctors. Subsequent investment in the future through the employment of these doctors needs also to be assured. We call on the Department to use the means at its disposal to do this. (Paragraph 167)
28. Overall we believe a long-term commitment by the Department to build a modern national allergy service would be the appropriate response to the current situation. Achieving this aim is clearly a long-term endeavour starting from the current very low base of provision. But the problems are not going to go away; indeed, they will increase, given trends in disease prevalence. So we believe a start must be made now. It is important not to fragment the use of scarce resources, so we believe leadership around an integrated strategy is vital, and call on the Department to produce a strategy statement indicating how it proposes to develop allergy services, taking account of all the proposals in the RCP document, as well as those contained in our report. The first essential element needs to be the creation of regional specialist centres to lead and to underpin service development across the whole country and to secure the resources for these in ways that will give everybody confidence in their continued existence in the NHS. But change needs to go beyond this. It needs to be sustainable within the devolved processes for the modern service. It may be that, as happened with cancer services, an individual, or small group of individuals, could be assigned a specific role to drive through policy change, and provide the millions of allergy sufferers with the appropriate provision for their condition, a provision which is currently largely absent from the NHS. We would like to see proposals from the Department which will bring allergy services into the mainstream of NHS care and a mechanism to ensure their implementation. (Paragraph 169)

# Annex: analysis of memoranda from individuals to the inquiry

Of the 338 submissions we received from individuals who provided histories of their, or their children's, experiences of allergy we analysed 201.

- 24% male patients (or on behalf of male patients)
- 76% female patients (or on behalf of female patients).

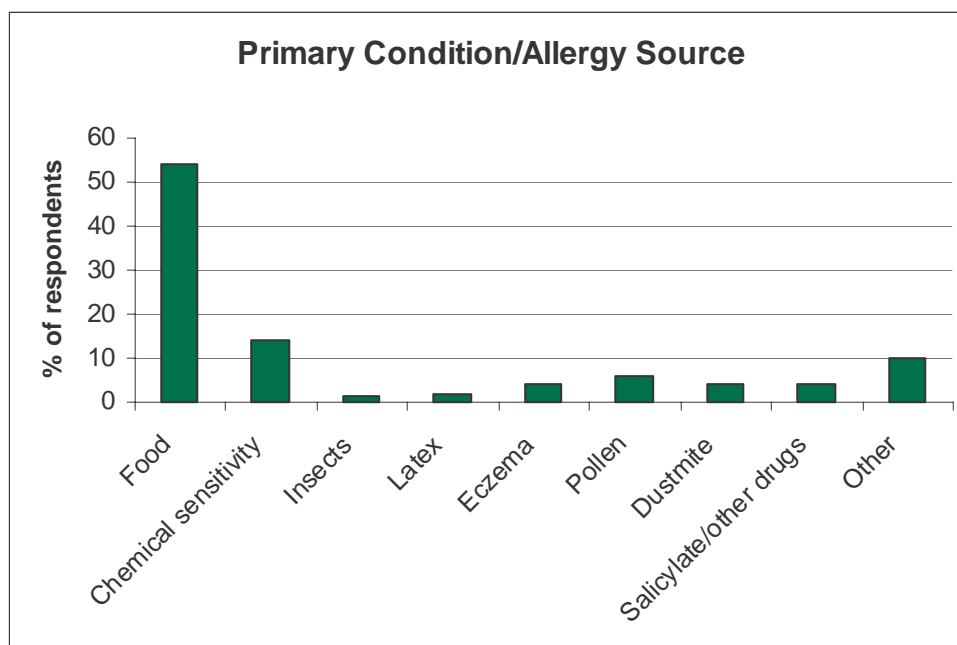
**Patient origin:**



**Primary condition/source of allergy (as reported by patient)**

| Condition/source of allergy | No. of patients | Percentage |
|-----------------------------|-----------------|------------|
| Food                        | 102             | 54         |
| Chemical sensitivity        | 27              | 14         |
| Plants/pollen               | 11              | 6          |
| Salicylate and other drugs  | 8               | 4          |
| Dustmite                    | 7               | 4          |
| Eczema                      | 7               | 4          |
| Latex                       | 4               | 2          |
| Insects (anaphylaxis)       | 3               | 1.5        |
| Urticaria (weals/rash)      | 3               | 1.5        |
| Mercury                     | 3               | 1.5        |
| Animals                     | 2               | 1          |
| Moulds                      | 1               | 0.5        |
| Dystonia                    | 1               | 0.5        |
| Others                      | 10              | 5          |

N.B. most people with allergy react to multiple allergens. Not all submissions detailed this point.

**Diagnosis**

Only 23% of patients received a correct diagnosis of allergy when they first presented to their GP. The majority (77%) received an incorrect diagnosis and many visited their GP on

many occasions, often over a period of years, before a correct diagnosis was made or a referral issued.

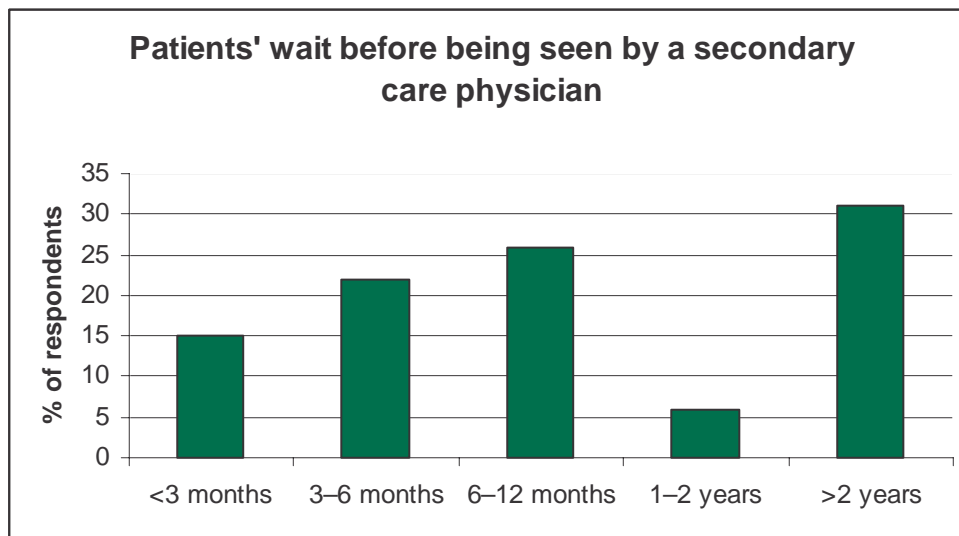
**Availability of specialist allergy (or immunology) service**

Of 150 allergy patients who mentioned this point in their submissions, 62 (42%) had been referred to some type of allergy service while 85 (58%) had not. It should be noted that several patients mentioned that they were only referred after specifically requesting it from their GP, often having been given the name of a relevant consultant and hospital by Allergy UK.

**Time to referral to (non-private) secondary care**

This data includes, but is not exclusive to, specialist allergy or immunology services. Patients were also referred by their GPs to dermatologists, chest physicians and ear, nose and throat specialists, among others. This pattern of referral was due in part to the lack of allergy services in their areas.

The graph below shows the time that patients had to wait before being seen by a secondary care physician.



Total patients who mentioned this data in their submission: 85

| Waiting time | Number of patients | Percentage |
|--------------|--------------------|------------|
| < 3 months   | 13                 | 15%        |
| 3-6 months   | 19                 | 22%        |
| 6-12 months  | 22                 | 26%        |
| 1-2 years    | 5                  | 6%         |
| > 2 years    | 26                 | 31%        |

### **Private care**

A total of 45% of patients reported being forced to seek care in the private sector for their allergies. Blood testing by York Laboratories (usually at a cost in excess of £200) was particularly common.

### **Other points**

It may be worth noting that 9% of patients mentioned in their submissions that they had tried complementary and alternative medicine, particularly homoeopathy. Worryingly, 6% of patients had been prescribed antidepressants or referred to psychiatric services at some point during their care.

### **Particular issues**

The following is a list of areas that caused particular distress to patients:

- Lack of information, particularly regarding potential treatments for allergy, such as desensitisation;
- Lack of knowledge in the primary care sector regarding allergy generally;
- Disbelief among GPs of reported symptoms (many patients mentioned being laughed at by their doctors when they made suggestions regarding their symptoms or possible avenues of care);
- Lack of support and subsequent feelings of isolation.

The necessity for better food labelling, more research and funding was stressed by many individuals.

## List of abbreviations used in the report

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|       |   |
|-------|---|
| A&E   | Accident and Emergency                              |
| BSACI | British Society for Allergy and Clinical Immunology |
| ENT   | Ear, Nose and Throat                                |
| GPwSI | General Practitioner with Special Interest          |
| HRG   | Health Resource Group                               |
| IgE   | Immunoglobulin E                                    |
| NASG  | National Allergy Strategy Group                     |
| NSCAG | National Specialist Commissioning Advisory Group    |
| PCT   | Primary Care Trust                                  |
| RCP   | Royal College of Physicians                         |
| RCPCH | Royal College of Paediatrics and Child Health       |
| SHA   | Strategic Health Authority                          |

## Formal minutes

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**Tuesday 12 October 2004**

Members present:  
Mr David Hinchliffe, in the Chair

Mr David Amess  
John Austin  
Mr Keith Bradley  
Mr Simon Burns

Mrs Patsy Calton  
Mr Jon Owen Jones  
Dr Doug Naysmith  
Dr Richard Taylor

The Committee deliberated.

Draft Report (The Provision of Allergy Services), proposed by the Chairman, brought up and read.

*Ordered*, That the Chairman's draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 169 read and agreed to.

Annex agreed to.

*Resolved*, That the Report be the Sixth Report of the Committee to the House.

*Ordered*, That the Chairman do make the Report to the House.

*Ordered*, That the Provisions of Standing Order No. 134 (Select Committee (Reports)) be applied to the Report.

*Ordered*, That the Appendices to the Minutes of Evidence taken before the Committee be reported to the House.

[Adjourned till Thursday 14 October at 10 am



## Witnesses

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### Wednesday 17 June 2004

Page

|  |       |
|--|-------|
| <b>Ms Muriel Simmons</b> , Chief Executive, Allergy UK, <b>Mr David Reading</b> , Campaign Director, the Anaphylaxis Campaign and <b>Dr Shuaib Nasser</b> , Consultant Allergist, Addenbrooke's Hospital.  | Ev 10 |
| <b>Professor Stephen Holgate</b> , Chairman, National Allergy Strategy Group, <b>Professor Andrew Wardlaw</b> , President, British Society for Allergy and Clinical Immunology, <b>Professor John Warner</b> , Paediatric Allergist, University of Southampton and <b>Dr Lawrence Youlten</b> , Consultant Allergist, London Allergy Clinic. | Ev 60 |

### Thursday 1 July 2004

|  |       |
|--|-------|
| <b>Rt Hon Dr Stephen Ladyman</b> , a Member of the House, Parliamentary Under-Secretary of State for Health, and <b>Mrs Patience Wilson</b> , Head, Programme National Service Framework for Long-Term Conditions. | Ev 75 |
|--|-------|

## List of written evidence

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|   |        |
|---|--------|
| 1 Allergy UK (AL77)   | Ev 1   |
| 2 The Anaphylaxis Campaign (AL31)                                     | Ev 2   |
| 3 The Anaphylaxis Campaign (AL31A)                                    | Ev 19  |
| 4 Dr Shuaib Nasser (AL72)   | Ev 27  |
| 5 National Allergy Strategy Group (AL19)                              | Ev 34  |
| 6 British Society for Allergy and Clinical Immunology (AL24)          | Ev 51  |
| 7 Professor John Warner (AL3)   | Ev 57  |
| 8 Dr Lawrence Youlten (AL58)  | Ev 58  |
| 9 Department of Health (AL10)   | Ev 71  |
| 10 Department of Health (AL10a)                                       | Ev 204 |
| 11 University of Manchester (AL1)                                     | Ev 89  |
| 12 Barts and the London NHS Trust (AL4)                               | Ev 90  |
| 13 South & West England & Wales Clinical Immunology Audit Group (AL5) | Ev 91  |
| 14 Dr Michael Tettenborn (AL6)  | Ev 91  |
| 15 NHS Grampian (AL7)   | Ev 92  |
| 16 North-West Lung Clinic (AL9)                                       | Ev 93  |
| 17 British Association of Dermatologists (AL11)                       | Ev 102 |
| 18 Norfolk Allergy Diagnostic and Advisory Service (NADAAS) (AL12)    | Ev 103 |
| 19 Dr Tina Dixon (AL13)   | Ev 105 |
| 20 Royal Brompton and Harefield NHS Trust (AL14)                      | Ev 106 |
| 21 Dr Philip Doré (AL15)  | Ev 107 |
| 22 Professor Tak Lee (AL16)   | Ev 108 |
| 23 Dr Chris Corrigan (AL17)   | Ev 110 |

|    |  |        |
|----|--|--------|
| 24 | North of England Clinical Immunology Audit Group (AL20)                        | Ev 113 |
| 25 | Dr R S H Pumphrey (AL21)   | Ev 116 |
| 26 | Professor T J David (AL25)   | Ev 118 |
| 27 | Doris M Jones MSc (AL26)   | Ev 120 |
| 28 | Professor A B Kay (AL27)   | Ev 123 |
| 29 | Dr Vibha Sharma (AL28)   | Ev 123 |
| 30 | Maureen Jenkins (AL30)   | Ev 124 |
| 31 | Dr Gideon Lack (AL32)  | Ev 125 |
| 32 | Elizabeth Murphy (AL33)  | Ev 126 |
| 33 | Bedford Allergy Support Group (BASG) (AL34)                                    | Ev 126 |
| 34 | Royal College of Paediatrics and Child Health (AL2)                            | Ev 129 |
| 35 | Queen's Medical Centre Nottingham, University Hospital NHS Trust (AL35)        | Ev 132 |
| 36 | Tayside University Hospitals (AL36)  | Ev 133 |
| 37 | Dr Edward Kaminski and Christine Symons (AL39)                                 | Ev 141 |
| 38 | Lancashire Teaching Hospitals (AL40)   | Ev 142 |
| 39 | Dr Nigel J N Harper and Dr Richard Pumphrey (AL41)                             | Ev 144 |
| 40 | Alan M Edwards (AL42)  | Ev 145 |
| 41 | Dr Julia Clark and Professor Andrew Cant (AL43)                                | Ev 146 |
| 42 | Mr Malcolm Stamp CBE (AL44)  | Ev 149 |
| 43 | Professor Anthony Frew (AL45)  | Ev 152 |
| 44 | Dr Paul Cullinan (AL46)  | Ev 156 |
| 45 | Dr Mazin Alfaham (AL47)  | Ev 156 |
| 46 | Dr Rita Brown FRCP (AL48)  | Ev 158 |
| 47 | Dr Andrew Clark (AL49)   | Ev 159 |
| 48 | Dr Adrian Morris (AL50)  | Ev 159 |
| 49 | Dr Katherine Sloper (AL51)   | Ev 161 |
| 50 | Asthma UK (AL52)   | Ev 163 |
| 51 | Dr Penny Fitzharris (AL53)   | Ev 165 |
| 52 | Anaphylaxis Campaign and Allergy UK (AL55)                                     | Ev 166 |
| 53 | Royal College of Physicians (AL55)   | Ev 168 |
| 54 | Dr G Scadding (AL56)   | Ev 183 |
| 55 | The British Society for Allergy, Environmental and Nutritional Medicine (AL59) | Ev 184 |
| 56 | Dr Amolak Bansal (AL60)  | Ev 191 |
| 57 | Dr Jonathan Hourihane (AL61)   | Ev 191 |
| 58 | Professor Aziz Sheikh (AL62)   | Ev 193 |
| 59 | Margaret Moss (AL64)   | Ev 195 |
| 60 | Dr Tim Wallington (AL65)   | Ev 195 |
| 61 | Dr Alaisdair Stewart MD FRCP (AL66)  | Ev 197 |
| 62 | Dr G P Spickett and Dr A Fay (AL68)  | Ev 197 |
| 63 | Dr D E Lacy, Dr J Seager and Mr A Bardsley (AL69)                              | Ev 199 |
| 64 | Professor J Buckley (AL70)   | Ev 202 |
| 65 | Latex Allergy Support Group (AL71)   | Ev 202 |
| 66 | Mid Sussex NHS Primary Care Trust (AL77)                                       | Ev 204 |

## List of unprinted written evidence

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Additional papers have been received from the following and have been reported to the House but to save printing costs they have not been printed and copies have been placed in the House of Commons library where they may be inspected by members. Other copies are in the Record Office, House of Lords and are available to the public for inspection. Requests for inspection should be addressed to the Record Office, House of Lords, London SW1. (Tel 020 7219 3074) hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

Elizabeth Murphy  
Mrs J I Constable  
B Eyre  
Mrs M J Stow  
Kathryn Bailey  
Joyce Morrow  
Jack Codman  
Ian & Pam Williams  
Ms Pauline Jones  
Mrs R S Beeny  
Mrs D J Colman  
Mrs P L Williams  
Julie Owens  
Mrs Rosemary Nichols  
S A Priton  
Wendy Longman  
Christine Skelton  
Mrs Janet Cooper  
Mr & Mrs P R Davey  
Mr J G Cooper  
Katherine Trafford-Owen  
Maureen Wiseman  
Joan Thomas  
Joan Walpole Reilly  
Mr T Rombach  
Mrs P Ranson  
Mrs G C Nullens  
Mrs L A Bell  
Mrs C Webster  
Mrs Rita Cox  
Jennifer Howells  
Mrs Frances Rabone  
Helen Wallace  
Heather Campbell  
Denise Hunt/Matt Kelly  
Mrs Suzanne Khechy  
Mrs L Wellings  
Mr & Mrs Doran  
Miss Susan Radcliffe  
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Mr A H Griffith-Jones  
Iain Esau and  
Saramma Thomas-Esau  
Mrs A Mills  
Mrs Shirley Cleverdon  
P L G and C A Hayman  
Jane Redfern  
J Benson  
Jean M Stephenson  
Mr Eric Birbeck  
Jane Bishop  
Mr Ed Debaes  
J C Buckley  
Clare Pritchard

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V Bailey  
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A S Cromarty  
Mrs Clare Turner  
Pamela M Gallon  
Patrick Webster  
Des Seymour  
Miss Beatriz Rodriguez  
Mrs K Farr  
B Wyatt  
Mrs Hazel Brackley  
Mr & Mrs L G Barr  
Lynett Williams  
Mrs Frances Hutton  
Mrs S Mitchell  
Mrs Headland  
Mrs C Musson  
Mrs Rhoda Noble  
Marjorie Roff  
Mrs Allison Frazier  
Mrs Dorothy E Fowler  
A Bourne  
Paul Senior  
Alison Inglis  
Verity Chilver  
Elaine Plant  
Mrs Judy Smith  
Jackie Banham  
Mrs C L Davies  
Mrs A Snow  
Mrs C A J Burns  
Mr Brian J Naylor  
Mrs Karen Green  
Mrs A V Hommel  
Helen Handman

|                          |                        |                    |
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| Mrs M Collier            | Jeanette Fenner        | E English          |
| Mr & Mrs Holt            | Mr T Hughes            | J Riches           |
| E Margaret Gooneratne    | Mrs E Baker            | L Swain            |
| Dr P E Williams          | Beverley Appleton      | P Schmidt          |
| Muriel A Simmons         | Mary Hill              | A Marshment        |
| Mrs I M Wood             | D V Gawn               | J Coote            |
| Gisele Cole              | Lynn Macgill           | J Martin           |
| Miss Margaret J Reichlin | Mrs Michelle Curtis    | P Williams         |
| Mrs D Harrington         | Mrs L Cope             | C Wilson           |
| Joan Ingham              | Mrs Jane Hume          | J Whelbourn        |
| Miss Louise Hunt         | Mrs Donna E Scotter    | F M Pitchford      |
| Caroline F Miller        | Mrs Mieczyslawa Pascoe | A Pargeter         |
| Mrs Diane Hibbert        | Gill Dodsworth         | J Parker           |
| G & A Owen               | Mrs C Rosen            | S Davies           |
| Jennifer Brown           | John Telford           | J E & S E Phillips |
| Gillian Fox              | Mrs Z Clarke           | A Jones            |
| Clare Gaen               | Miss Susan J Tupper    | D & S Cox          |
| Sheena Fisher            | Mrs Jean Atkins        | R Cowley           |
| Mrs Shelagh Woolley      | Elizabeth Waldron      | N Clark            |
| Mrs Elizabeth Pogson     | R F Howard             | Dr G Scott         |
| Gail Peake               | T Barrow               | Dr M Lucey         |
| Bree Evans               | J Claydon              | A Franks           |
| Eric Jethro              | S Rawlinson            | O Sanderson        |
| Ivan Bexon               | M McLaughlin           | J Hancox           |
| Phyllis Marian Torry     | J Pope                 | S K Osborne        |
| Mrs L Pillinger          | J Rablin               | A Waghorn          |
| Mrs Marion Hughes        | M Murray-Palmer        | C George           |
| Mrs Angela Kilmartin     | C B Jordan             | J & N Colesby      |
| Julian Berry             | J Quipp                | A M Clarke         |
| Mrs Angela Cox           | E M Taylor             | H Green            |
| Mrs Maxine Zeltser       | C Monk                 | A Andrews          |
| Mrs Linda Tress          | G Chegwyn              | D Barker           |
| Martin O'Leary           | A Clarke               | L Thomas           |
| Mrs C M Beaver           | R Spencer              | P Kissagizlas      |
| Mrs M H Talbot           | M Oliver               | P S Diver          |
| Mrs Brenda Andrews       | S Field                | N Le Jeune         |
| Janet Miller             | T Ryder                | S Moore            |
| June Mills               | D Shilling             | A Green            |
| Doreen Thorpe            | C Stokoe               | S Scarratt         |
| Miss Julie Barnham       | M & J Armer            | S Lane             |
| Mrs T E Godfrey          | J E Sandall            | C Williams         |
| Caroline Stephenson      | C Hislop               | L Smith            |
| J Reshelt-Thomas         | L Clendon              | L John             |
| Mrs C A Ashworth         | J Gokcen               | N Freeman          |
| Mrs Shiela Wheatcroft    | C Sadler               | L Castillo         |
| John Rowley              | B Saul                 | S P Bell           |
| Christine Fitzmaurice    | S McCloskey            | E Yamson           |
| Mr Keith Barnsley        | S C Baxter             | M Riley            |
| Muriel Jones             | A Clarke               | N Hillyard         |
| Miss Denise Dolan        | V Dand                 | J Tasker           |

|                      |               |
|----------------------|---------------|
| H Legg               | D Horn        |
| R A Ford             | P M Whitaker  |
| L Garner             | P J Lomas     |
| A Hamilton           | A E E Russell |
| M Solk               | C d'Aboville  |
| M King               | W D Sly       |
| J Stevenson          | A McAllister  |
| Dr C Clifford        | J K Davis     |
| D G Gardiner         | M Dixon       |
| G Isaacs             | R Gibbs       |
| M Le Resche          | E & S Colley  |
| G R Lander           | K Yule        |
| R Hedderman          | D M & G Kelly |
| J McIntosh           | C S Leaver    |
| P L Williams         | W Smith       |
| P Allen              | H Duncombe    |
| J Scott              | C & C Phipps  |
| L M Hughes           | S J Tomlinson |
| C Orme               | T Kettle      |
| L A Robinson         | J Gibbons     |
| A Pledge             | J R Murray    |
| V Fordham            | E E Reeves    |
| A Keeling            | C Butler      |
| B Shenyill           | P White       |
| F M Murray           | J Harbottle   |
| F Easey              | B Graham      |
| D M E Gordon         | S Lefley      |
| J M Evans            |               |
| I, V & L Newman      |               |
| C Micallef & A Yenez |               |
| W J Cleghorn         |               |
| B Huxley             |               |

# Reports from the Health Committee since 2001

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The following reports have been produced by the Committee since the start of the 2001 Parliament. The reference number of the Government's response to the Report is printed in brackets after the HC printing number.

## Session 2003–04

|               |                                  |                  |
|---------------|----------------------------------|------------------|
| First Report  | The Work of the Health Committee | HC 95            |
| Second Report | Elder Abuse                      | HC 111 (Cm 6270) |
| Third Report  | Obesity                          | HC 23            |
| Fourth Report | Palliative Care                  | HC 454 (Cm 6327) |
| Fifth Report  | GP Out-of-Hours Services         | HC 697 (Cm 6352) |

## Session 2002–03

|                |   |                  |
|----------------|---|------------------|
| First Report   | The Work of the Health Committee  | HC 261           |
| Second Report  | Foundation Trusts   | HC 395 (Cm 5876) |
| Third Report   | Sexual Health   | HC 69 (Cm 5959)  |
| Fourth Report  | Provision of Maternity Services   | HC 464 (Cm 6140) |
| Fifth Report   | The Control of Entry Regulations and Retail Pharmacy Services in the UK | HC 571 (Cm 5896) |
| Sixth Report   | The Victoria Climbié Inquiry Report                                     | HC 570 (Cm 5992) |
| Seventh Report | Patient and Public Involvement in the NHS                               | HC 697 (Cm 6005) |
| Eight Report   | Inequalities in Access to Maternity Services                            | HC 696 (Cm 6140) |
| Ninth Report   | Choice in Maternity Services  | HC 796 (Cm 6140) |

## Session 2001–02

|               |  |                  |
|---------------|--|------------------|
| First Report  | The Role of the Private Sector in the NHS  | HC 308 (Cm 5567) |
| Second Report | National Institute for Clinical Excellence | HC 515 (Cm 5611) |
| Third Report  | Delayed Discharges                         | HC 617 (Cm 5645) |