NHS SCOTLAND

Children & Young People's Allergy Network Scotland

CYANS Secondary Care Survey

Evaluation Report 2013

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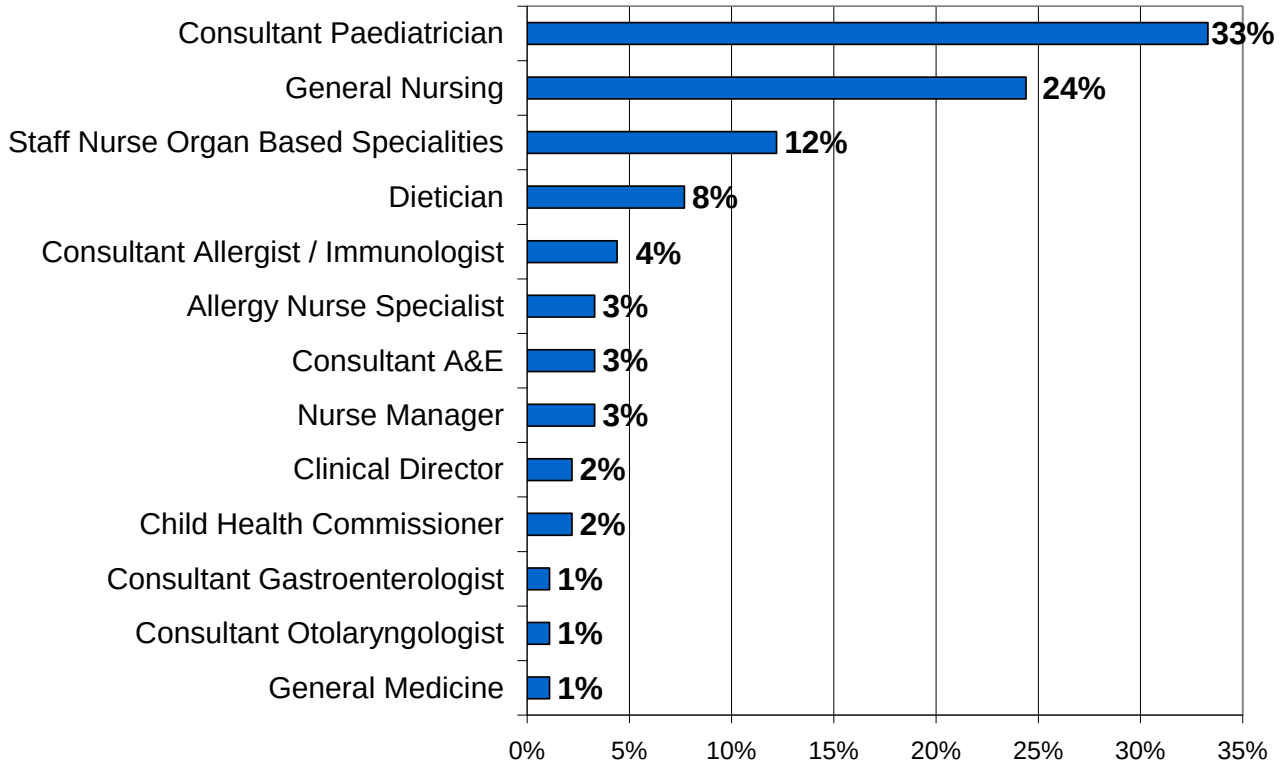
1. Introduction and aims of the survey

The aim of the survey was to identify the current provision of allergy services for children and young people across Scotland, define any areas for improvement or gaps in allergy service provision, including looking at opportunities for the development of transition services. CYANS designed a questionnaire to be completed by health care professionals who were involved in the treatment and management of children and young people with allergies across secondary care services in Scotland, in order to capture as wide a geographical and health care professional picture as possible to accurately map service provision. The survey was sent to identified contacts within secondary and tertiary care in allergy and organ based specialties within each health board in Scotland, and where responses were fewer than expected, CYANS members and child health commissioners within the identified health board were targeted until a satisfactory response was achieved. The survey was available on line between July to November 2012.

Response to the survey
A total of 90 clinicians from all 14 NHS Scotland health boards responded to the questionnaire. The majority of respondents were consultant paediatricians and paediatric nursing staff, but respondents also included clinicians from organ based specialities, allergy / immunology specialist clinicians, A&E clinicians, clinicians from general medicine and health care planners.

Role of respondents to survey



2. Patterns of allergy care provision in secondary care

- 44% of respondents see children and young people with allergies in general paediatric clinics, 22% see them in specialist allergy clinics. Children and young people are also seen within dietetic led clinics, organ based speciality clinics including dermatology, respiratory, ENT and gastroenterology clinics and A& E, therefore obtaining a clear picture of where children and young people with allergies are seen is challenging (*see appendix 1 & 3*).

- 54% of respondents surveyed see allergic emergencies or children with acute anaphylaxis

- 86% of clinicians have dietetic support available if required.

- 55% have never used psychology support for allergy patients but 20% are aware it is available in their area.

- Specific IgE blood testing is the preferred option for diagnostic testing for allergy, followed by food challenges and skin prick testing

- The majority of referrals for allergic conditions are referred to dedicated allergy services, where provision is available locally, where no provision is available children and young people are referred to general paediatric clinics.

- The main reason for referral of patients with allergy within secondary care is cited as insufficient expertise

- 70% of secondary care clinicians are not able to refer young people to adult services; the majority of young people are referred back to their GP for follow up care.

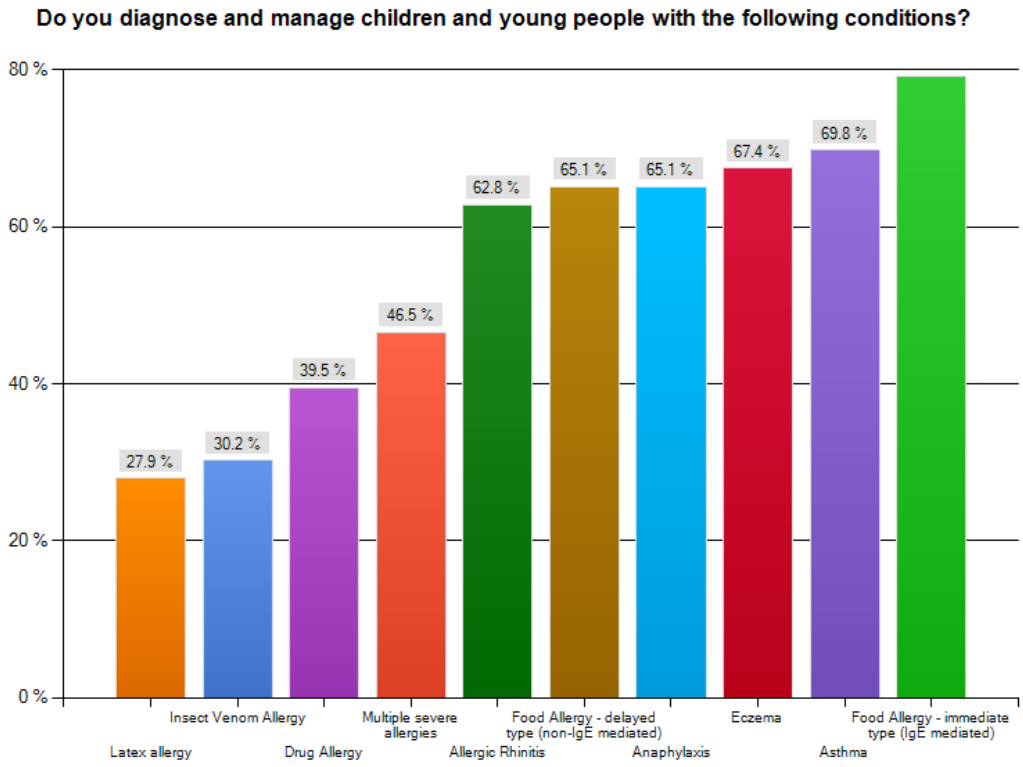
- The majority of health care professionals (80%) provide verbal and written allergy information and advice to patients and their families.

3. Diagnosis and Management

In secondary care the survey suggests immediate type food allergy is the condition most commonly diagnosed and managed by most respondents 79% (*Graph 1*), with 62% seeing up to 10 patients a week (*Graph 2*).

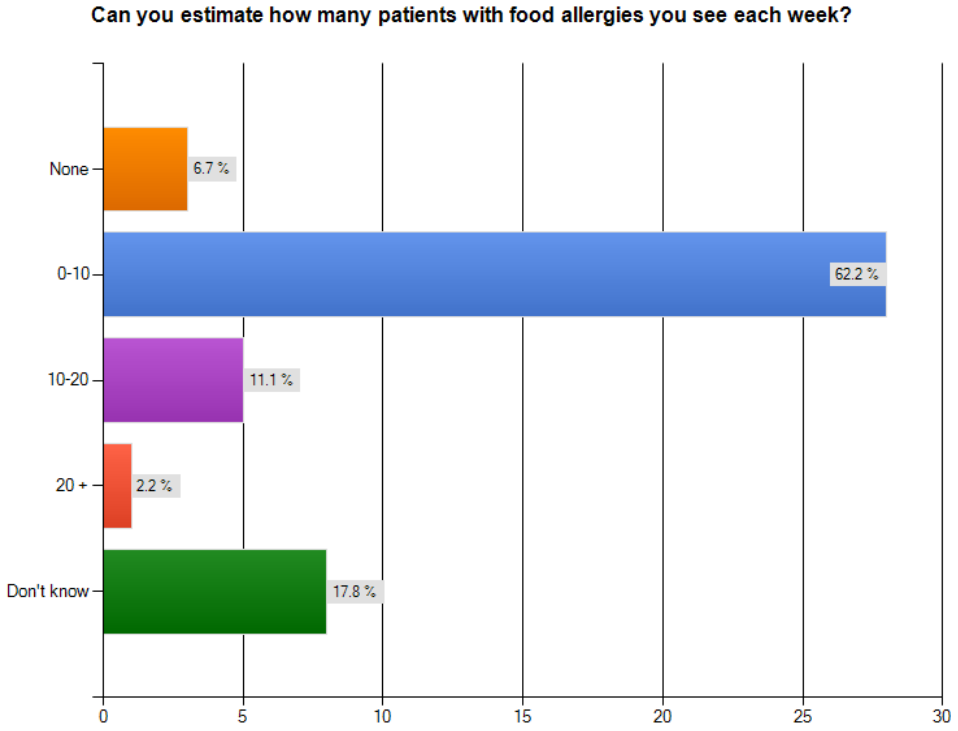
The majority of clinicians (86%) stated they have access to paediatric dietetic support when required, however 78% of respondents stated patients would require a separate visit to receive dietetic support.

Graph 1



Graph 2

Food allergy



Management of anaphylaxis

- The majority of respondents treat children with adrenaline as the drug of first choice.
- Antihistamines and corticosteroids are rarely used as the drugs of first choice for anaphylaxis.
- The majority of clinicians record the clinical signs and symptoms of a suspected anaphylaxis, but do not always record the time of onset of reaction and the patient's circumstances prior to the onset of the reaction to help identify the trigger allergen.
- Mast cell tryptase for suspected insect venom, drug or idiopathic anaphylaxis are rarely taken in children (8%).
- The majority of respondents (54%) admit children under 16 under the care of the paediatric team after treatment for suspected anaphylaxis.

Patients / parents / carers are not always:

- Offered a referral to specialist allergy service after a suspected anaphylaxis,
- Offered a demonstration on the correct use of adrenaline auto-injectors.
- Given information on emergency and avoidance measures
- Given information on biphasic reactions
- Given Information on support groups

4. Referrals **(appendix 3)**

- The majority of respondents refer (e.g. to allergy service, organ specialities) within the clinician's own health board. Where there are no professionals with the necessary knowledge in allergy services within the local area, referrals are made out with the health board and occasionally patients are referred out with Scotland if services (e.g. insect venom, immunotherapy) are not available at the local tertiary centre.
- Respondents usually refer anaphylaxis to paediatric allergy (41%) or general paediatrics (19%)
- The majority of respondents children with asthma, eczema and allergic rhinitis to organ based specialities if required.
- Most respondents refer immediate type food allergy (IgE mediated) to paediatric allergy (59%) with 17% referring to dietetic services
- The majority of respondents refer delayed food allergy (non IgE) to paediatric allergy (42%) or dietetic services (42%)
- Most respondents (76%) refer children and young people with multiple severe allergies appropriately to paediatric allergy and only 18% referring to general paediatrics, possibly where no allergy service is available within the health board.
- The majority of respondents refer children and young people with latex (70%), drug (82%) or insect venom allergy (83%) to paediatric allergy where this service exists within the health board.

The main reason for referral was cited as insufficient expertise across all conditions.

Transition to adult allergy services

- 70% of secondary care clinicians do not refer young people to adult services with the majority of young people referred back to their GP for follow up
- "No adult service to refer to" was identified as the main reason for not referring young people.

5. Diagnostic services

- Specific IgE blood testing is the preferred option for diagnostic testing for allergy (85%), followed by food challenges (82%) and skin prick testing (77%).
- Drug and latex challenge were only available in selected health boards and required a referral.
- Inhaled allergen and nasal allergen challenge were not offered in any peadiatric unit as a diagnostic service.
- Specific IgE tests were offered by the clinician on the same day with 90% of clinicians feeling confident to interpret the results.
- Skin prick testing was most likely to be offered on the same day and completed by the multidisciplinary team in the majority of health boards with 76% of clinicians feeling confident to interpret skin prick testing.
- Some supervised food elimination diets and challenges for non IgE mediated allergy could be performed the same day where facilities were present, but all IgE mediated food challenges required a separate visit. 79% of clinicians felt confident to interpret food challenges.

Table 1 **Diagnostic tests**

Diagnostic tests	Yes	NO	Refer	When offered	Competence in interpreting results
Skin prick test	77%	23%	14%	41% Same Day 59% Separate Visit	76% Fully Competent 21% Partially Competent 3% Not Competent
Specific IgE (RAST)	85%	15%	13%	83% Same Day 17% Separate Visit	90% Fully Competent 7% Partially Competent 3% Not Competent
Patch test	23%	77%	75%	10% Same Day 90% Separate Visit	45% Fully Competent 33% Partially Competent 22% Not Competent
Food challenges IgE	82%	18%	33%	0% Same Day 100% Separate Visit	79% Fully Competent 21% Partially Competent
Supervised food elimination and re-introduction - delayed allergy	69%	31%	8%	42% Same Day 58% Separate Visit	60% Fully Competent 32% Partially Competent 8% Not Competent
Latex challenge	9%	91%	46%	9% Same Day 91% Separate Visit	72% Fully Competent 18% Partially Competent 10% Not Competent
Drug challenge	9%	91%	38%	9% Same Day 91% Separate Visit	70% Fully Competent 20% Partially Competent 10% Not Competent
Nasal allergen challenge	0%	100 %	100 %	0% Same Day 100% Separate Visit	100% Not Competent
Inhaled allergen challenge	0%	100 %	100 %	0% Same Day 100% Separate Visit	100% Not Competent

Immunotherapy
Immunotherapy is only available within the following tertiary allergy centres for paediatric allergy.

- RHSC Yorkhill: Sublingual and subcutaneous pollen/ Subcutaneous insect venom
- RHSC Edinburgh: Sublingual grass pollen
- Ninewells Hospital: Sublingual grass pollen

6. Information and Support for patients and their families

The response to the survey indicates that all health boards provide information and support to patients and their families

80% of respondents provide both written and verbal advice to patients and their families on the use of adrenaline auto injectors, emergency management of allergic reactions and food allergen avoidance advice**.**

For patients given advice, this is given on the same day for over half of the respondents by the attending clinician (30-40%) or a member of the multidisciplinary team (50-60%).

Between 20% - 40% of respondents stated that patients and families would need to return for a separate visit for education and advice in the use of adrenaline auto-injectors, emergency management advice and food allergen avoidance advice, with a member of the multidisciplinary team. It is noted from the response to this survey that in areas where there is no dedicated allergy service available all patients have to return for a separate visit for education and advice.

7. Most important improvements **(see appendix 4)**

The most important improvements to allergy services identified by respondents were:

- Dedicated specialist allergy nurse available where allergy services are provided.
- Paediatric consultant or clinician with appropriate training in allergy available in each health board
- Multidisciplinary “one stop shop” allergy clinics available in each health board including dietetic support
- Increased provision of dietetic support

Most important improvements suggested for tertiary allergy centres included:

- Access to immunotherapy
- Increased number of dedicated specialists in paediatric allergy

Continued links and involvement with CYANS was highlighted as an important resource for health care professionals responses included;

- Continued links with NMCN paediatric allergy for ongoing training, shared protocols and guidelines
- Standardised patient information to be made available via CYANS website

8. Recommendations for secondary care

- Adequate number of clinicians with appropriate training in allergy in each health board to provide high quality secondary allergy care for their patient population.

- Provision of a specialist allergy nursing services within each health board, to work between primary and secondary care.

- Development of a multidisciplinary one stop allergy clinic within each health board that currently provides allergy care.

- Adequate access to a dietician with experience in the management of food allergy within each health board.

- Provision of formal training opportunities for paediatric consultants with an interest in allergy to develop and advance their skills.

- Each health board should have a clear pathway into an allergy service staffed by professionals with the necessary knowledge and skills to manage the broad range of allergic conditions, this pathway should include arrangements for :
    - follow up management
    - referral of children and young people with severe/complex allergies
    - children who would benefit from immunotherapy

- There should be adequate numbers of consultants with specialist allergy training to support this pathway and provide tertiary services for those with complex and specialised service needs

Appendix 1 Current allergy provision in Scotland (separate page)

The following paediatric hospitals have been identified as providing tertiary care for children and young people with allergies

Allergy service provision in tertiary care

- ***Royal Hospital for Sick Children – Yorkhill, Glasgow***

Allergy service is led by 2 consultant paediatric immunologist/allergists with sessions from 2 general paediatricians with an interest in allergy providing “inreach”, a full time nurse practitioner in allergy and 2 nurse practitioners in ambulatory care with sessions in allergy. An additional consultant in general paediatrics with an interest in allergy is about to be appointed. “One stop” clinics are held with nurse and dietician input.

Yorkhill sees paediatrics up to the age of 13 years and takes tertiary referrals from NHS Lanarkshire, Ayrshire & Arran, Forth Valley, Dumfries & Galloway, Highlands and the Western Isles.

- ***Royal Hospital for Sick Children – Edinburgh***

Allergy service is led by a part time honorary consultant paediatric allergist with part time general paediatrician with interest in allergy (1 session per week), 1 full time allergy nurse specialist and part time allergy specialist dietician (0.5 FTE). Multi disciplinary clinics are provided with dietetic support.
RHSC Edinburgh sees paediatrics up to the age of 16 years and takes referrals from NHS Borders and Fife.

- ***Ninewells – Dundee***

Allergy service is led by a consultant paediatrician with an interest in food allergy (1 session per week) with specialist allergy nurse input (0.5 FTE) and a multidisciplinary clinic session with dietetic support.

Ninewells Hospital sees paediatrics up to the age of 16 years and takes referrals from NHS Fife.

- ***Royal Aberdeen Children's Hospital***

Allergy service is led by a specialist allergy nurse (0.5 FTE) and paediatric respiratory consultant (1 session per month), dietetic input is available as required.

RACH sees paediatrics up to the age of 16 years and takes referrals from NHS Orkney, Shetland and Highland.

Allergy service provision in secondary care

Table 2 outlines paediatric allergy services within the district general hospitals (DGHs) in Scotland,

Table 2 **Allergy service provision in secondary care**

NHS Health board and Hospital	**Peadiatric consultant With special interest in allergy**	**Allergy Nurse Support**	**Dietetic support available at clinic same day**
NHS Ayrshire & Arran Crosshouse Hospital Kilmarnock	Yes patients seen in allergy clinics	no	As required
NHS Borders Borders General Hospital	Yes patients seen in allergy clinics	no	no
NHS Dumfries & Galloway Dumfries & Galloway Royal infirmary	yes	No	no
NHS Forth Valley Forth Valley Royal hospital Larbet	Yes patients seen in general paediatrics	No	No
NHS Fife Victoria hospital Kirkcaldy	Yes patients seen in allergy clinics	yes	yes
NHS Greater Glasgow and Clyde Royal Alexander Paisley	Yes patients seen in allergy clinics	no	As required
NHS Highlands Raigmore Hospital Inverness	no	no	no
NHS Lanarkshire Wishaw General Hospital	Yes patients seen in allergy clinics	yes	yes
NHS Lothian St Johns Hospital Livingston	Yes patients seen in allergy clinics	no	no
NHS Orkney Balfour Hospital Kirkwall	no	no	no
NHS Shetland Gilbert Bain Hospital Lerwick	no	no	no
NHS Tayside Perth Royal Hospital	Yes patients seen in allergy clinics	yes	As required
NHS Western isles Western Isles Hospital Stornaway	no	no	no

Please note - All health boards also see children and young people with allergies within general paediatric clinics, also organ based paediatric speciality clinics including dermatology, respiratory, ENT, gastroenterology and ophthalmology. Thus, obtaining a clear picture of where patients with allergy are seen and the numbers of allergy patients seen is challenging.

Appendix 2
Adult allergy services
The following table outlines adult allergy / immunology service facilities in Scotland. Please note adult immunology / allergy services have limited capacity for referral for young people with allergy and the service is limited to multiple severe allergies, anaphylaxis where need is identified, therefore follow up care after initial assessment is not always available in all areas

Table 3 adult allergy services

NHS HB Hospital	**Greater Glasgow & Clyde** West of Scotland Anaphylaxis Service (WOSAS) Western General Hospital Gartnavel hospital Victoria Hospital.	**Lothian** Edinburgh Royal Infirmary	**Tayside** Ninewells Hospital Dundee	**Grampian** Aberdeen Royal Infirmary
Referral age	Allergy referrals from age 13 years upwards	Allergy referrals from age 16 years up	Allergy referrals from age 16 years up	Allergy referrals from age 16 years up
Consultant allergist / immunologist	None Service is led by respiratory consultant 3 anaphylaxis clinics per week plus asthma and allergy clinic sessions	N/A	1 session per week	2 sessions per week
Other medical	2 session per week - GP with interest 6 sessions per week - Associate specialist 1 session per week - Other consultant 4 sessions 1 staff grade 1 session per month - dermatology	Dermatology 1 session per month Patients also seen through general medicine or respiratory medicine where appropriate	ENT 1 session per weeks (3.5 hours per week)	
Immunology Allergy nurses	50% WTE	N/A	No dedicated nursing staff	14 hours per week
Dietitian	5 session per week Adolescents and adults	No dedicated sessions	No dedicated sessions	No dedicated sessions
Technician	N/A	N/A	Available for skin prick testing	N/A
Referral Process	Self referrals Primary care A&E	Primary care A&E Organ based specialities	Primary Care A&E, Organ based specialities, Anaesthetics occupational health	Primary Care A&E, Organ based specialities Anaesthetics Occupational health

Appendix 3

Table 4 **Referral patterns for individual allergic conditions across secondary care in Scotland**

Condition (No of responses)	**Never referred**	**Sometimes referred**	**Always referred**	**Referral to which department**	**Reason for referral**	**Health board**
Asthma (34)	41%	59%	0%	74% Paediatric Respiratory 21% General Paediatrics 5% Peadiatric Allergy Clinic	70% insufficient expertise	95% in own HB 5% out with HB
Allergic Rhinitis (34)	56%	44%	0%	64% ENT 29% General Paediatrics 7% Peadiatric Respiratory	82% insufficient expertise	93% in own HB 7% out with HB
Eczema (37)	24%	73%	3%	79% Dermatology 8% Paediatric allergy 4% General Paediatrics	79% insufficient expertise	100% seen in own HB
Food allergy IgE (36)	43%	44%	14%	59% Paediatric allergy 17% Dietetic Services 8% Specialist Nurses 18% General Paediatrics	58% insufficient expertise 33% insufficient personnel 33% Insufficient facilities	88% seen in HB 12% out with HB
Food allergy delayed (35)	51%	37%	11%	42% Paediatric Allergy 42% Dietetic services 8% Gastrointestinal 8% General Paediatrics	56% insufficient expertise 44% insufficient personnel 11% Insufficient facilities	92% seen in HB 8% out with HB
Anaphylaxis (34)	41%	27%	32%	75% Peadiatric allergy 6% Specialist Allergy Nurse 19% general Paediatrics	53% insufficient expertise 47% insufficient personnel 47% Insufficient facilities	81% seen in HB 14% out with HB 6% out with Scotland
Latex allergy (31)	52%	29%	19%	70% Paediatric Allergy 10% Allergy /	67% insufficient expertise	90% seen in HB 10% out

				Immunology 10% Allergy Nurse 10% other	25% insufficient personnel 17% Insufficient facilities	with HB
Drug Allergy (31)	45%	42%	13%	82% Paediatric Allergy 9% Allergy / Immunology 9% Specialist Nurses	75% insufficient expertise 25% insufficient personnel 17% Insufficient facilities	55% seen in HB 36% out with HB 9% out with Scotland
Insect Venom Allergy (30)	43%	27%	30%	83% Paediatric Allergy 8% Specialist Nurses 8% General Paediatrics	62% insufficient expertise 39% insufficient personnel 30% Insufficient facilities	61%Seen in HB 31% out with HB 8% out with Scotland
Multiple severe allergies (32)	35.5%	35.5%	31%	76% Paediatric Allergy 6% Specialist Nurses 18% General Paediatrics	59% insufficient expertise 47% insufficient personnel 24% Insufficient facilities	65% seen in HB 29% out with HB 6% out with Scotland

* **Table 4 indicates percentages of respondents who stated that they refer children and young people within specialist services.**

Appendix 4

Table 5 Most important improvements to allergy service provision in your area

AREAS	SUGGESTED IMPROVEMENTS
Service Provision	
Dedicated Specialist Allergy nurse	• Referrals • Approach for information and advice • Specialist outreach clinics - e.g. SPT, Investigations • Increased sessions
Dietician	• Dedicated and or Increased dietetic support - • Increased dietetic time • Food challenges / challenges provided locally
One stop allergy clinic	• Dietetic input • Medical review • Diagnostic testing • Allergy management on same day - (save child and family multiple visits- especially remote and rural - patients can travel distance)
Multi disciplinary approach	• meetings to provide consistent and coordinated approach to management across specialities
Dedicated Paediatric Consultant with interest in allergy	• to manage complex / complicated patients
Transition services	• Adolescent transition clinic
Adult allergy Service	• Develop service locally
Investigations	• provided locally
Established service	• **Increase** number of allergy clinic sessions
Guidelines & Pathways	
Clear referral pathway	• including guidelines on follow-up
Allergy referral pathways	

Allergy action plans	• primary to secondary care • for patients
<u>Treatment</u> **Immunotherapy** **Sublingual Immunotherapy**	• funding on NHS
<u>Training</u> **Formal training for paediatricians in allergy** **Training pack for staff** **Increased awareness and skills in primary care**	• managing allergies / anaphylaxis in primary Care
<u>Remote and Rural</u> • One stop allergy clinic	• Programmed activities in job plan for local consultant with interest in allergy • Dedicated allergy nurse • Improved teleheath facilities • Telephone and email support for clinicians for complex cases