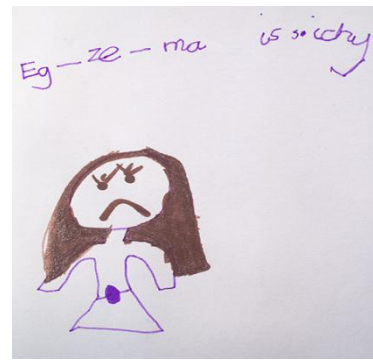


# Shaping the Future of Allergy Care for Children and Young People in Scotland

The CYANS Recommendations for a  
Model of Allergy Care for Scotland

2013





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Special thanks go to the children, young people and their families who provided the information and drawings contained in this report, Gordon Brown Director of Asthma UK Scotland for working with CYANS on this collaboration, various departments within NHS Lothian including Kenny Marshall for the design graphics, Clifford Burden for communications, James Glover for leading the impact assessment and all other departments who have assisted with the layout and content of the report including graphs, maps and administrative support, NHS National Services Scotland (NSS), The University of Edinburgh, Asthma UK Scotland, The Anaphylaxis Campaign and YoungScot.

## Executive summary

Allergies have become increasingly frequent and now affect one in three children and young people in Scotland. Most have mild to moderate allergies which could be adequately managed in primary care. However a significant group of 2-3% of children and young people suffer from complex and severe allergy including anaphylaxis and need specialist allergy care. Previous reports including the 2009 SMASAC report, identified inequalities and gaps in allergy service provision in Scotland and deficiencies in allergy training and expertise in both primary and secondary care.

To start addressing issues of availability and quality of allergy care for children and young people in Scotland the Children and Young People's Allergy Network Scotland (CYANS) was formed as a pan-Scotland project network within the structure of a National Managed Clinical Network (NMCN) and supported by funding from the National Delivery Plan for Paediatric Specialist Services. CYANS' remit has been to lead improvements in allergy care with a focus on severe allergy, to establish the evidence base that underpins sustainable coordinated development and delivery of allergy care, and to address known issues in allergy care that have been highlighted by previous reports.

Through successful engagement with a wide variety of stakeholders across Scotland including children, families and young people with allergies, clinicians treating allergies, health care planners, the voluntary sector and allergy researchers, and through the use of focus groups and questionnaires CYANS was able to gather patients' and clinicians' views on current allergy services, obtain information on current patterns of allergy care in primary care, map secondary and tertiary care allergy service provision across Scotland, and understand education and training needs of clinicians providing allergy care. The main findings were:

- Allergy can have a major impact on daily living, emotional and social wellbeing for children, young people and their families.
- Families and young people with allergies do not feel sufficiently supported by clinical services or in schools. They wish for increased allergy awareness amongst the general public and require access to reliable allergy information.
- Allergy care is important for most primary care clinicians but very few have allergy expertise, while the majority request additional allergy education and training.
- Secondary care allergy service provision varies greatly between the geographically diverse health boards in Scotland.
- There is insufficient capacity in adult allergy services to provide adequate care for the majority of young people who need to transition from paediatric allergy services.

To start addressing shortcomings in allergy care for children and young people CYANS has:

- Created a website to provide easily accessible and reliable allergy information for children, young people and their families as well as clinicians.
- Developed and agreed clinical recommendations for the management of anaphylaxis and food allergy to promote consistency in allergy care throughout NHS Scotland.
- Developed and successfully piloted an allergy training package for primary care clinicians.
- Developed an allergy database, using the clinical audit system as a platform. Data collection with an initial focus on anaphylaxis has begun and this database will support future service planning, quality improvement and allergy research.

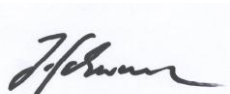
Based on findings from the initial project phase and agreement between stakeholders CYANS proposes an integrated equitable model of high quality allergy care that will provide



easily accessible competent diagnosis, treatment and management of frequent allergic conditions in primary care, access to state-of-the-art secondary and tertiary allergy care when required, and evidence based allergy advice to support patient self-management. To achieve such high quality allergy care across Scotland CYANS makes the following key recommendations to the Scottish Government:

- 1. Improve the standard of knowledge of allergy and provide education and training for all clinicians working with children and young people with allergies with an initial focus on primary care.**
- 2. Provide in all health boards a dedicated allergy service or identified adequately trained clinician in allergy to take allergy referrals in secondary care and to deliver allergy care as close to home as possible.**
- 3. Develop clear referral pathways through primary, secondary and tertiary care to clarify access to allergy services, including transition arrangements to adult services.**
- 4. Increase allergy awareness amongst health care professionals and education staff to enable them to respond appropriately to allergic reactions and to acknowledge and lessen the impact that allergy can have on the patient and their family.**
- 5. Develop and make easily accessible appropriate evidence based allergy information for all health care professionals to standardise the quality and level of information given to patients and their families.**
- 6. Continue to maintain and develop the CYANS allergy database and ensure data collection to aid planning of allergy service provision, quality improvement and audit, and research into allergy with an initial focus on anaphylaxis and food allergy.**
- 7. Designate CYANS as an NMCN to facilitate implementation of these recommendations and to develop CYANS as a central point of contact for information, guidance and resources for allergy in Scotland.**

The achievement of these ambitions for high quality allergy care and allergy awareness will require effective structures, systems, processes, and most importantly the right people. Through the work undertaken to date these are already in place and CYANS is an established and proven vehicle for driving service improvement.



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# 1. Introduction

The prevalence of allergic disease has increased dramatically over the last 3-4 decades, with allergies currently estimated to affect 30% of the UK population with approximately 1 in 3 children and young people in Scotland affected by allergy<sup>1,2</sup>. Allergic reactions can range from mild rashes and sneezing attacks to distressing widespread hives and skin swelling, breathing difficulties and in the most severe cases life threatening allergic reactions called anaphylaxis.

Although the majority of children with allergies will have symptoms that are mild to moderate, there is a considerable group of children and young people (2-3%) with severe allergic diseases. In these children allergy is usually a multi-system disorder that typically affects the skin with eczema, the lungs with asthma and the nose and eyes with hay fever or perennial (year round) allergic rhinitis. All of these manifestations can be severe and difficult to treat and lead to intense symptoms including itchiness, irritability, coughing, wheeze, breathlessness, and a restricted ability to exercise. Very often these children also suffer from immediate food allergies, usually to several different foods at the same time and often to staple foods, making avoidance difficult. Others have associated allergies to latex, bee and wasp stings, drugs or animals. Considerable numbers of children with severe allergies experience anaphylaxis or are at risk of this life threatening form of allergic reaction. In children, food is the most common trigger for anaphylaxis<sup>3, 4</sup>.

Allergies are known to reduce the quality of life, affecting a child's or young person's physical, social, and emotional wellbeing including relationships, and may impair their school performance<sup>5, 6</sup>. Therefore it is essential that we develop a cohesive pathway of care, involving health care professionals, schools, parents, and children and young people themselves, that provide:

- Dedicated, easily accessible, high quality allergy care for all children and young people in Scotland including transition services
- Education and training to all those involved in providing care for children and young people with allergies
- Easily accessible evidence based allergy information for children and young people and their families.

While the majority of children and young people with mild to moderate allergies can be managed adequately in primary care, those affected severely require treatment by clinicians specialising in allergy. Current access to specialised paediatric allergy services across Scotland varies greatly. In addition, the majority of children with common allergic conditions also deserve high quality allergy care provided by primary and secondary care clinicians. Therefore all clinicians who treat and manage children and young people with allergies need to be equipped with the appropriate skills, knowledge and support systems to enable them to diagnose, manage and treat allergic conditions to help reduce the considerable burden of allergy and improve the quality of life of affected children, young people and their families.

Paediatric allergy was identified as a specialty requiring support by the National Delivery Programme for Children's Specialist Services (NDP), as a result of previous 'allergy reports' including the House of Lords report (2007)<sup>7</sup> and the Scottish Medical and Scientific Advisory Committee (SMASAC) report (2009)<sup>8</sup>, which supported the development of a National Managed Clinical Network (NMCN) approach to improve allergy service provision across Scotland. While paediatric allergy is different from a number of other paediatric specialist services supported by NMCNs, in that there are large numbers of children and young people with allergies, but only few clinicians specialised in allergy, a recent very encouraging report (2011) from the North West England Allergy and Clinical Immunology Network<sup>9</sup> evidences

the benefit of a network approach, but acknowledges that *“it is important to note that networks are not a quick fix but a more long term solution to the problems surrounding allergy service provision”*.

### **1.1 Approach: the Development of CYANS**

In 2010 NDP funding was secured to develop a pan-Scotland paediatric allergy network and as a result the Children and Young People’s Allergy Network Scotland (CYANS) was established in June 2011 to lead improvements in paediatric allergy care. In a departure from the standard NMCN model an initial discrete two year programme of work was outlined:-

- To establish the evidence base for a sustainable and coordinated pan-Scotland approach to the ongoing development and delivery of allergy care
- To address known issues in allergy care highlighted in previous reports, as set out in section 11.

CYANS was tasked to make recommendations to the Scottish Government based on the initial work programme and to establish itself as a full NMCN.

In order for CYANS to begin addressing the key concerns in allergy care provision across Scotland NMCN-based governance was established with a Lead Clinician, an Allergy Advisor, a Steering Group and Working Group Leads. Multidisciplinary working groups were established to take forward specific streams of work in the following key areas:

- Development of a model of high quality allergy care including allergy pathways, recommendations for allergy care and a review of specialised allergy services.
- Definition of allergy education and training needs for health care professionals and develop training solutions.
- Development of a robust system of data collection for allergy to aid service planning, audit and research.
- Improvement of communication and information sharing with all CYANS stakeholders, including the development of a website and newsletters.

To ensure that the work was achievable within the initial two year programme, CYANS focused its work on anaphylaxis and immediate type food allergy. In the longer term CYANS intends to extend its focus to encompass complex multi system allergy and immediate type allergy to latex, insect venom and drugs.

### **1.2 Stakeholder engagement in CYANS**

To develop high quality allergy care across Scotland it is essential that this care is centred on patients and their families, provided by a well-trained multidisciplinary clinical team, informed by state-of-the-art allergy knowledge and clinical practice, and feasible within NHS Scotland. It was therefore necessary to obtain views and opinions from patients and their families, clinicians, academics and health care planners to ensure that their views and needs are reflected in future allergy care. All of these stakeholders were involved in CYANS’ work through participation in CYANS working groups and in its steering committee. They were also invited to attend focussed discussions at CYANS events, respond to CYANS questionnaires, and contribute to the CYANS web site.

## 2. Allergy experiences of children, young people and their families



CYANS has, over the course of the last two years, devoted time to try and find out what effect allergy has on a child, young person and their families and what support they require to help them lead happier, healthier lives. CYANS devised ways to capture their views and opinions on current paediatric allergy services in Scotland and their aspirations for future allergy care. This work ensures that the patients' and families' needs and views are reflected in CYANS work and recommendations for future allergy care provision.

### **2.1 What we did**

Children, young people and their families were invited to contribute and to make their views known in a variety of ways. These included:

- Focussed discussions at the CYANS launch event in Glasgow in March 2012.
- 'Family days' in Aberdeen, Glasgow and Edinburgh run by experienced allergy nurses to facilitate discussions and provide allergy advice.
- Questionnaires for family members, including a joint venture with YoungScot, aimed at young people.
- Opportunity to send articles and drawings or cartoons to express '*what allergy means to me*' for the CYANS 'Living with Allergy' project.

The views and opinions of children, young people and parents are described in detail in the patient and public involvement report (CYANS Patient and Public Involvement Report Dec 2012).

[http://www.cyans.scot.nhs.uk/files/cyans\\_i\\_would\\_like\\_cakes\\_report\\_2012.pdf](http://www.cyans.scot.nhs.uk/files/cyans_i_would_like_cakes_report_2012.pdf)

### **2.2 Quality of life**

Research findings indicate that having a food allergy can have a profound impact on the whole family including feelings of anxiety and stress affecting not only the parents but siblings and close family members as well. Furthermore, recent research has found that having a severe food allergy has a greater impact on the individual's quality of life than diabetes mellitus<sup>12</sup>.

Children and young people were asked at CYANS events to describe their feelings on having an allergy and how they feel it affects them in everyday activities. Many of the comments were very negative including feelings of frustration, anxiety, social exclusion (not being invited or not wanting to participate in parties or social activities which include food) and feeling different from their peers.

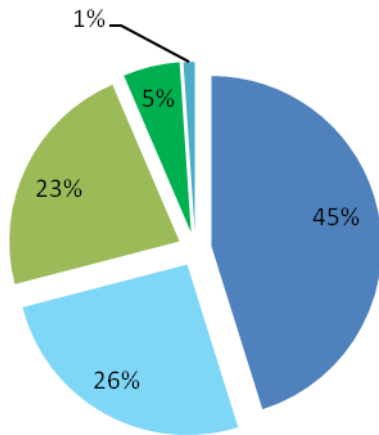
Similar feelings and issues became apparent in a survey that CYANS developed in partnership with YoungScot to gather information on young people's experiences of living with allergy and the impact that allergy has on their lives. Responses were obtained from 136 young people ranging from 11-19 years of age across a wide range of health boards.

[http://www.cyans.scot.nhs.uk/files/cyans\\_young\\_peoples\\_views\\_report\\_2013.pdf](http://www.cyans.scot.nhs.uk/files/cyans_young_peoples_views_report_2013.pdf)

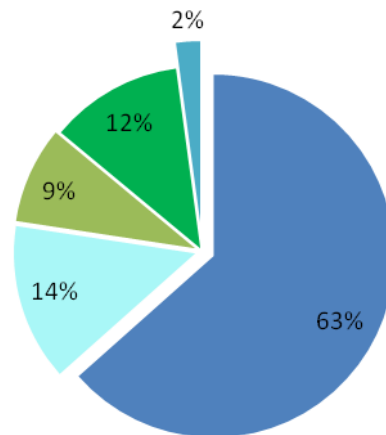
Impact of allergy on my social life

Young people were asked to respond to the following statements related to the question - *How does having an allergy affect your social life?*

Having an allergy stops me joining in with friends



Having an allergy stops me eating out with friends



- This never happens
- This happens rarely
- This happens some of the time
- This happens most of the time
- This happens all of the time

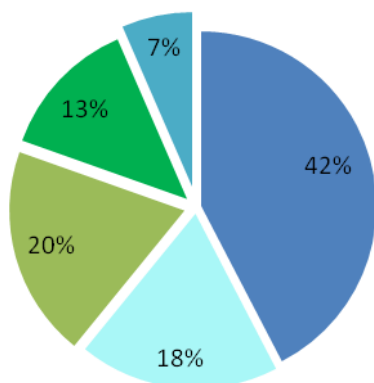
Half of the respondents to the survey felt that having an allergy did impact on their social life, with 28% who felt that they don't always cope well with their allergies and 29% who felt that having allergies can stop them joining in activities with friends, including 37% who felt that having an allergy had stopped them eating out with friends and 14% who felt that having an allergy made it more difficult to make friends.

How does it make me feel...?

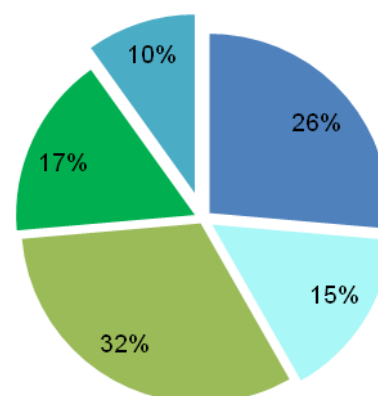
Young people were asked to respond to the following statements related to the question – *How does living with allergy make me feel...?*

The survey indicates 53% of respondents felt that they were proud with the way they coped with their allergies, although 47% stated they don't always feel they cope well with their allergies. 31% did not always feel supported by family and friends, however 69% did feel supported the majority of the time by family and friends. Over 30% of respondents reported having felt down or sad as a result of living with their allergies, 36% having felt embarrassed, 38% reported feeling different and 47% have felt frustrated and fed up. 40% stated that living with an allergy makes them feel anxious or stressed and 59% have felt annoyed or irritated due to their allergies.

Living with an allergy makes me feel anxious/stressed.

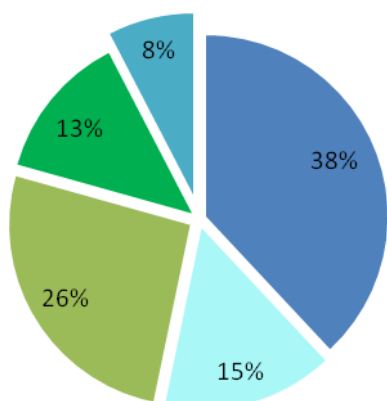


Living with allergy makes me feel annoyed/irritated.

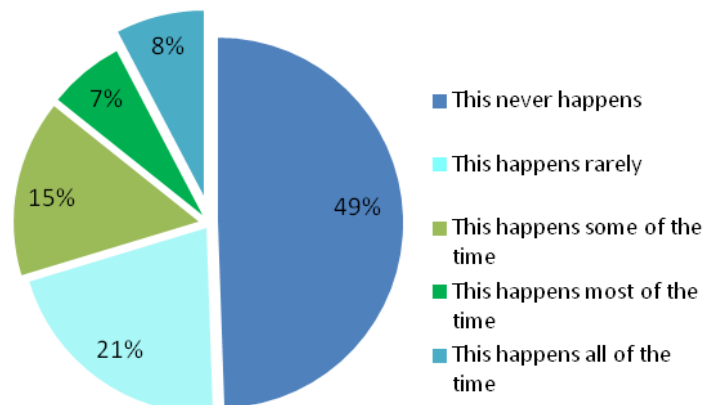


- This never happens
- This happens rarely
- This happens some of the time
- This happens most of the time
- This happens all of the time

Living with an allergy makes me feel frustrated/ fed-up.



Living with an allergy makes me feel down/sad.



### **2.3 Allergy Support**

When asked what would be the ideal solution for those living with allergy, the natural reaction was 'not having allergies'. Accepting that this is not realistic, the following areas for improved allergy support were highlighted:

#### **Children (aged 3-11 years) wanted:**

- Better support for siblings to enable them to help where possible.
- Not to feel different to their friends.
- Parents not to worry about them.

#### **Young people's (12-19 years) wishes included:**

- Increased public awareness about allergy and effects of allergy on everyday living.
- Everyone being informed as to how to deal with allergy and having an allergic reaction.
- Improved support networks, e.g. support groups, available locally.
- Increased understanding of severe allergies amongst the public, GPs, hospital clinicians, and staff in catering, hospitality and on planes.
- Improved labelling, range, variety and availability of foods for 'free from' diet for people with food allergy.
- Access to support groups/contact others with similar age and allergies.
- Science behind allergy: "know why the body becomes allergic".

#### **Support in schools requested by children and young people**

- Support at school – a buddy system to meet others with allergy.
- Friends and classmates being educated about allergy, including how to manage an allergic reaction.
- Information for school staff on the importance of emergency medication and training.
- Involvement of schools in developing allergy care.
- Education of all staff from nursery onwards.

Agreement was that if more people were informed and educated about allergy, especially in school or areas where food was accessible socially, like restaurants and recreational franchises (e.g. cinemas), then living with allergy would become easier.

### **Parents**

During the consultation process the parents identified a need for access to consistent, reliable allergy information, specifically on:

- Management of allergic reactions.
- Growing up with allergy, and relationships and allergy.
- Recipes/information on how to cook for allergies.
- Lists of common food allergens and alternative names.

They also specifically requested:

- Age appropriate information
- Access to support groups (for all family members).
- Approved websites and information leaflets.
- Improved packaging and labelling of 'free from' foods.

### **2.4 Clinical Allergy Service**

Young people and parents were asked what they felt would improve their clinical allergy service.

### **Young People**

Young people requested:

- Access to adult allergy services.
- A named clinician to contact for support.
- Health care professionals to be more responsive and flexible in approach when caring for young people.

### **Parents**

The majority of parents (75%) do not feel they are getting the information and support they need. Parents and young people requested that health care professionals have an appreciation of the psychological and social issues they face in everyday living and that they understand that allergy, in particular severe allergy, affects all aspects of life and the whole family.

When asked to outline what an ideal allergy service would look like the following suggestions were made:

- Consistent care and improved communication– see same clinician on more than one occasion.
- Access to care when needed including 'Out of Hours' support
- Access to a properly funded dedicated allergy service. A 'one stop shop' service that provides the appropriate investigations for allergy, with an allergy consultant, nurse specialist, dietician available if required, to end the need for multiple attendances at clinics
- Clinicians who have an appreciation of the psychological and social aspects of living with or caring for a child with allergy.
- Clear referral pathways and consistent guidelines e.g. prescribing adrenaline auto-injectors (AAIs).
- End to delays in referrals and treatments
- Education for primary care/education staff
- Consistency of information provided by clinicians.
- A database of competent health care professionals for GPs to contact for advice.

## **2.5 Recommendations**

- **CYANS to continue gathering children's, young people's and families' views on allergy care throughout its life span to ensure that these are reflected in service development and delivery.**



### 3. Views of health care professionals on allergy care



Having obtained a service users view from patients and families we approached clinicians to seek their views on potential problems and gaps in allergy care throughout Scotland. This information was collected via focus groups with both primary and secondary care clinicians involved in allergy care. Clinicians were asked what issues / barriers they have encountered; where they felt there were gaps or areas for improvement; what they considered to work well within their area and to suggest solutions for an ideal allergy service and allergy education.

#### **3.1 Allergy service provision**

Some of the common obstacles and barriers identified included:

- Lack of specialised adult and/or paediatric allergy services.
- GP issues – lack of knowledge/reluctance to refer.
- Poor information and support.
- Lack of knowledge on what is available.
- Lack of dietetic support.
- Patients feel pushed towards private care/treatment.

The ideal allergy service was generally defined amongst primary and secondary care clinicians as including:

- More allergy support within community to be able to diagnose and manage within primary care rather than refer to secondary care.
- Improved communication within primary care.
- The ability to cross-refer within primary care (i.e. to a practice with special interest).
- Early and timely access.
- Improved patient pathways between primary care, secondary care and for transition to adult allergy service.
- Work with the voluntary sector and signposting patients and professionals to their services appropriately.
- Focus on psychology/psychological impact of allergy.

Solutions that were highlighted included:

- Clear national guidelines and referral pathways including access to specialist allergy services for more complex allergy.
- Standardised care plans/management plans for patients including a school management plan.
- A standard information pack for patients and families to improve consistency of information.
- Multidisciplinary clinics to improve coordination and communication and reduce number of appointments.
- Transition service development.

### **3.2 Allergy education and information**

Clinicians identified requirements for allergy education and information including:

- Clearer guidance on testing and referral process.
- Standardised allergy focussed history taking including a proforma.
- Dietetic information on food labelling, recipes, eating out, avoidance and food challenge support.

Delegates would like information delivered by:

- e-learning but also more practical local groups/ 1:1 training
- peer review system/case review
- use of telemedicine with links to specialist centres
- mentorship by multidisciplinary team
- practical workshops

Priorities for information were identified as:

- more primary care training
- accredited training/officially recognised - CPD accreditation
- access to training for professionals annually
- clinician resource list/map on website to identify what is available geographically
- development of a standard history taking proforma
- standardisation of information

The discussion sessions highlighted the difficulties that clinicians face in providing/ utilising allergy services and generated solutions as to how these issues could be addressed. Interestingly, all participants highlighted very similar problems due to inconsistency in the availability of allergy services, demonstrating clearly the importance of a focus on improving allergy services for the future.

## 4. Identifying current patterns of allergy care provision in Scotland

Allergy care for children and young people in Scotland is currently provided in both primary and secondary care, and for some also in specialised tertiary allergy centres. Given likely geographical variations in the provision of allergy care, it was important to map where, at what level, and by which clinicians this care is provided across Scotland. Such information is best obtained from the clinicians who provide the clinical care. Since the approach to and level of allergy care differs significantly between primary and secondary/ tertiary care we used separate surveys to gather information on allergy service provision from primary and secondary/tertiary care clinicians involved in managing children and young people with allergies. The extensive stakeholder engagement required for this mapping exercise enabled CYANS to create effective communication links with all sectors of allergy service provision.

### Primary Care

#### 4.1 Primary care survey

The primary care survey received a total of 95 responses from all health boards across Scotland, but one. Most respondents were general practitioners, practice and public health nurses and community dietitians.

[http://www.cyans.scot.nhs.uk/files/cyans\\_primary\\_care\\_survey\\_eval\\_report\\_2013.pdf](http://www.cyans.scot.nhs.uk/files/cyans_primary_care_survey_eval_report_2013.pdf)

98% of primary care clinicians feel that allergy care is important in primary care but only 14% have a clinician with allergy expertise working with their practice leaving the majority (86%) without direct access to allergy expertise.

Despite an apparent lack in allergy expertise, the majority of allergic conditions are diagnosed and managed within primary care.

#### ***A. Allergic conditions managed and services provided in primary care***

- 57% of respondents diagnose and manage children with anaphylaxis. Most of them (67%) manage only very few cases by themselves and appropriately refer most to secondary care. 19% of respondents, mostly from remote and rural areas, manage most or all anaphylaxis cases themselves in primary care.
- 95% of respondents prescribe adrenaline auto-injectors to children at risk of anaphylaxis. Such prescriptions must be supported by training of parents and young people in the use of these devices and in the emergency treatment of anaphylaxis, but only 41% of respondents have a clinician in their practice that can provide this essential training.
- While 51% of respondents diagnose and manage children with food allergies, 45% of these always refer IgE-mediated food allergy which in the majority of cases is likely to be simple uncomplicated food allergy, much of which could be managed in primary care.
- 73% of respondents have children with multiple food allergies in their practice. The presence of multiple food allergies is generally seen as an indication for referral to a specialised allergy service and 70% of these respondents manage very few of these patients by themselves. It is striking, that respondents from some health boards felt they have to manage these children within their practice as there is no service to refer to.
- The majority of respondents do not diagnose (81%) or manage (92%) children with severe allergies in their practice but appropriately referred them to secondary care.
- Only 5% of clinicians manage all children known to be at risk of anaphylaxis themselves, while most refer these children to general paediatric clinics, or specialist allergy services where these exist.
- None of the primary care clinicians have access to skin prick testing facilities. 85% of respondents have access to serum specific IgE testing in the diagnosis of allergy.

### **B. Referral practice**

The majority of referrals to secondary care are made to general paediatrics and in some health boards to allergy services where these are established.

58% and 67% of respondents refer anaphylaxis and IgE-mediated food allergy respectively to general paediatric clinics and 32% and 25% respectively refer to allergy clinics. The high rate of referrals to general paediatrics is likely to be due to the following factors

- An absence of allergy services in some health boards.
- Insufficient capacity of established allergy services.
- In some health boards the referral process from primary care is to general paediatrics by default
- Lack of awareness of existing local allergy care provision.

Referrals for asthma, eczema and allergic rhinitis are appropriately made to organ-based specialist service.

### **C. Problems with referrals**

Problems with referrals identified by respondents included:

- No allergy service to refer to.
- Patchy provision of allergy services across Scotland.
- Unaware of what allergy provision exists locally.
- Lack of confidence to request specialist allergy services (e.g. food challenges).

### **D. Issues with allergy service provision/ access to local allergy service**

Issues identified by respondents included:

- Dietetic provision or access to dietetic services was highlighted as poor, especially to support infants on food avoidance diets.
- Provision of allergy services locally was identified as an issue of concern by 65% of respondents, who stated that they do not have access to a local dedicated allergy clinic. In one health board the respondents felt that the service is not adequately funded to meet the demands of the geographical area it serves (which includes remote settings). Only 20% of respondents stated that they have access to a local dedicated allergy clinic for children aged 0-13 years and only 9% have access to a local dedicated allergy clinic for young people aged 14 -18 years.
- Prohibitive distance and long travel to nearest specialist allergy service was also raised as an issue, which is especially relevant to patients from rural and outlying areas.

The most important changes to allergy service provision suggested by respondents for their area were:

- Agreed referral protocols in place between primary and secondary care.
- Improved access to multidisciplinary support (e.g. dietetics).
- A local dedicated allergy service.

#### **4.1.1 Recommendations**

- **Provide in each health board a dedicated allergy service or identified clinicians adequately trained in allergy to take referrals from primary care.**
- **Establish in each health board a clear pathway into this allergy service. This pathway should include arrangements for referral of children and young people**

with severe / complex allergies and arrangements for follow up management.

- Provide easy access to resources, including management guidelines, to support the management of common allergic conditions.
- Ensure protected learning time and funding to allow clinicians in primary care to develop their skills and knowledge in allergy.
- Provide adequate numbers of nurses and dieticians with the appropriate experience to support management of children with allergies in the community.
- Increase allergy education and training opportunities, focusing on food allergy and anaphylaxis, for primary care clinicians.

## Secondary Care

### **4.2 Secondary care survey**

A total of 90 clinicians from all 14 health boards responded to the questionnaire. Most respondents were consultant paediatricians and paediatric nursing staff, but they also included allergy/immunology specialists and clinicians in organ based specialities, A&E, general medicine and health care planning.

[http://www.cyans.scot.nhs.uk/files/cyans\\_secondary\\_care\\_survey\\_eval\\_report\\_2013.pdf](http://www.cyans.scot.nhs.uk/files/cyans_secondary_care_survey_eval_report_2013.pdf)

#### **4.2.1 Tertiary and secondary paediatric allergy services in Scotland**

The following describes the current allergy service provision for children and young people in secondary and tertiary care across Scotland. The information below is based on survey responses and on direct enquiry from clinicians providing allergy services.

##### **Royal Hospital for Sick Children Glasgow (Yorkhill)**

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

Yorkhill sees patients 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 led by an honorary consultant paediatric allergist, with 1 session/week from a general paediatrician with interest in allergy, a full time allergy nurse specialist, and a part time (0.5 FTE) allergy specialist dietician. Multidisciplinary “one stop” clinics are provided with dietetic support.

RHSC Edinburgh sees patients up to the age of 16 years and takes referrals from NHS Borders and Fife.

##### **Ninewells Hospital – Dundee**

Allergy service 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 patients up to the age of 16 years and takes referrals from NHS Fife.

### **Royal Aberdeen Children's Hospital**

Allergy service 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 patients up to the age of 16 years and takes referrals from NHS Orkney, Shetland and Highland.

### **District General Hospitals**

Dedicated allergy clinics are provided in the following DGHs

- NHS Ayrshire & Arran - Crosshouse Hospital -Kilmarnock
- NHS Borders - Borders General Hospital - Melrose
- NHS Dumfries & Galloway - Dumfries & Galloway Royal Infirmary - Dumfries
- NHS Fife - Victoria Hospital - Kirkcaldy #
- NHS Greater Glasgow & Clyde - Royal Alexander Hospital - Paisley #
- NHS Lanarkshire - Wishaw General Hospital - Wishaw #
- NHS Lothian - St John's Hospital - Livingston #
- NHS Tayside - Perth Royal hospital - Perth #

**Please note, # indicates dedicated allergy clinics with multi disciplinary support including consultant paediatrician with interest in allergy, specialist allergy nurse input and dietetic support.**

The health boards listed below do not have dedicated paediatric allergy clinics but see children and young people with allergies within general paediatric clinics:

- NHS Forth Valley - Forth Valley Royal Hospital -Larbert
- NHS Highlands - Raigmore Hospital - Inverness
- NHS Orkney - Balfour Hospital - Kirkwall
- NHS Shetland - Gilbert Bain Hospital - Lerwick
- NHS Western Isles - Western Isles Hospital -Stornaway

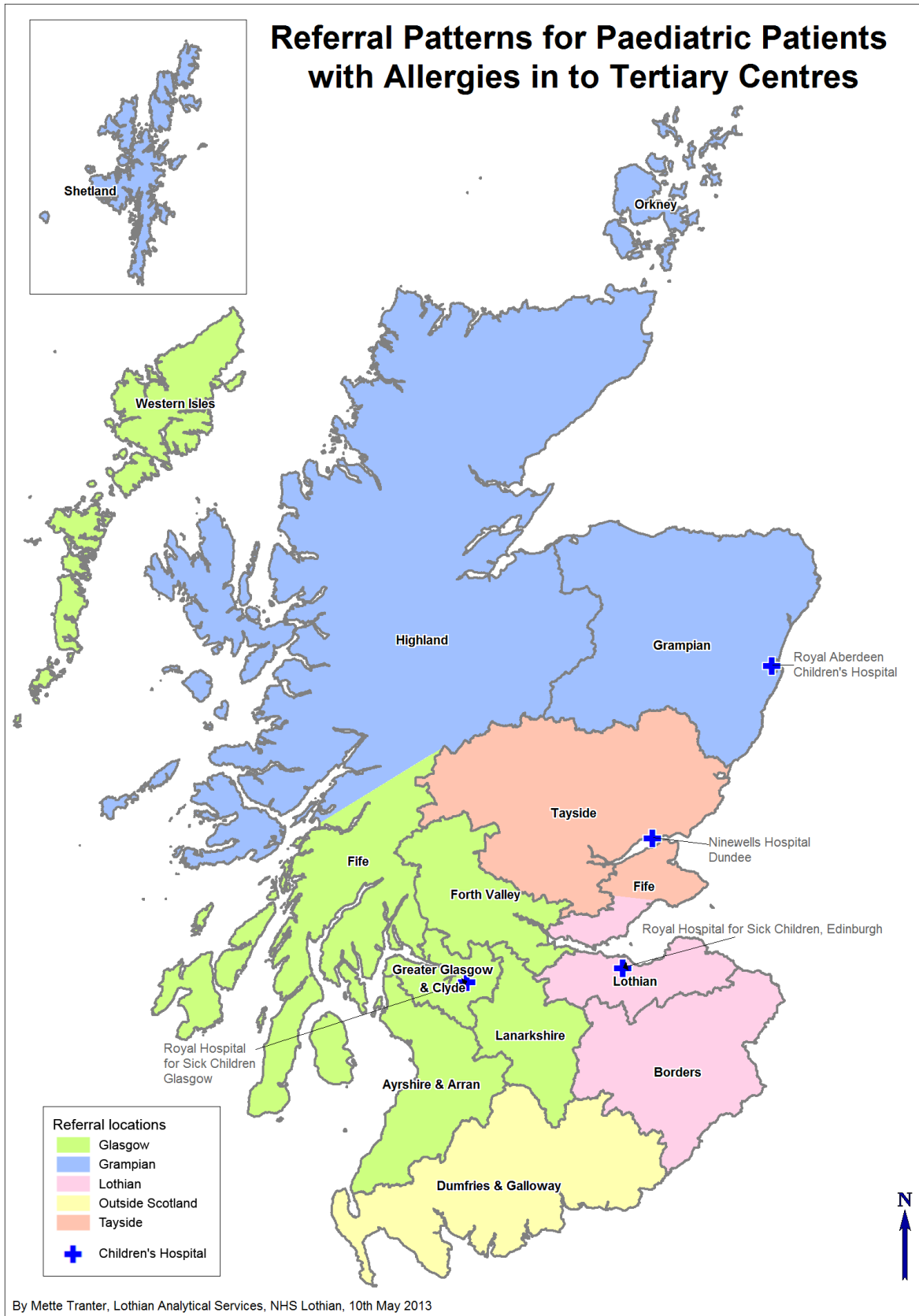
Additionally, all health boards see children with allergies within general paediatric clinics. (Please note children and young people with allergies are also seen in organ based paediatric speciality clinics including dermatology, respiratory medicine, ENT, gastroenterology and ophthalmology, thus obtaining a clear picture of numbers of allergy patients seen is challenging).

### **Referrals** (See map below)

The majority of referrals (e.g. to allergy service, organ specialities) are made 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 outside the health board and occasionally patients are referred outside Scotland if services (e.g. insect venom, immunotherapy) are not available at the local tertiary centre.

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

# Referral Patterns for Paediatric Patients with Allergies in to Tertiary Centres



#### **4.2.2 Patterns of allergy care provision in secondary care**

44% of respondents see children and young people with allergies in general paediatric clinics while 22% see them in specialist allergy clinics. Immediate type food allergy is the condition diagnosed and managed by most respondents (79%) with 62% seeing up to 10 patients a week.

##### **A. 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
- The majority of respondents admit children under 16 after treatment for suspected anaphylaxis.
- A referral to a specialist allergy service after a suspected anaphylaxis is not always offered.
- Information on the risk of a biphasic reaction is not always given.
- Information on support groups is not always given.

##### **B. Diagnostic testing**

Serum specific IgE testing is the preferred option for diagnostic testing for allergy, followed by food challenges and skin prick testing. Specific IgE tests are usually offered on the day of clinic appointment. 90% of clinicians feel confident to interpret specific IgE results, 76% skin prick test results, and 79% the outcome of food challenges.

##### **C. Support for patients and families**

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

86% of clinicians have dietetic support available if required.

40% of clinicians stated that they rarely use psychological support for allergy patients with the majority stating that they have never used or are unaware of psychological services for patients with allergy.

##### **D. 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 (after Individual Patient Treatment Request only)
- Ninewells Hospital: Sublingual grass pollen

##### **E. Most important improvements to allergy services identified by respondents:**

- 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

##### **F. Most important improvements suggested for tertiary allergy centres included:**

- Provision of immunotherapy in all tertiary centres



- Increased number of dedicated specialists in paediatric allergy

#### **4.2.3 Recommendations**

- Provide sufficient numbers of clinicians with appropriate allergy training in each health board to provide an adequate secondary allergy service for their patient population.
- Provide specialist allergy nurses in each health board, to work between primary and secondary care.
- Develop of a multidisciplinary 'one stop' allergy clinic in each health board that provides an allergy service.
- Ensure adequate access to a dietician with experience in the management of food allergy within each health board.
- Provide CPD opportunities in allergy for clinicians with an interest or specialised in allergy to develop and advance their skills.
- Each health board to establish 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
- Provide adequate numbers of consultants with specialist allergy training to support this pathway and provide tertiary services for those with complex and specialised service needs.

## 5. Transition to adult allergy care

It is widely acknowledged that the prevalence of allergic conditions is increasing amongst the paediatric population and this will have a major impact on the need for allergy services for young people and adults in the near future. The 2009 SMASAC report and work of CYANS have identified a shortage of specialist allergy services for young people and adults with severe allergies which constitutes a gap in service provision in Scotland.

In recent CYANS surveys (please see section 3 and 4) both primary and secondary care clinicians highlighted that in the majority of health boards there are no adult allergy services available to which to refer young people with allergies. 70% of secondary care clinicians do not refer young people to adult services but the majority of young people are referred back to their GP once they outgrow paediatric services. The existing adult allergy/immunology services (please see below), due to very high service demand and limited specialist capacity, are only able to accept referrals for the most severe forms of allergic disease (e.g. anaphylaxis) with limited facility for follow up and delivery of specialist or complex treatment options such as desensitisation. Existing capacity means that these services are unable to take any meaningful or strategic cross-boundary referrals for allergy patients. Respondents concluded that improvements to current allergy services should include the provision of adult allergy care and adolescent transition clinic arrangements for those individuals who have lifelong anaphylaxis or severe complex allergic conditions.

The need for additional adult services was also highlighted by the CYANS/Young Scot survey (please see section 2) and is supported by the following pertinent response to the question: *How do you think allergy care and support could be improved?*

***‘Provide an adult service as when I turned 18 I was left high and dry without full support’***

In addition, the responses to this survey indicated that young people would like an allergy service that is flexible according to their needs, with access to care when they need support, rather than routine follow up when they are well. Therefore the development of transition pathways for young people may need to include a flexible approach possibly providing drop-in-clinic options or access to an open appointment scheme to provide care when needed.

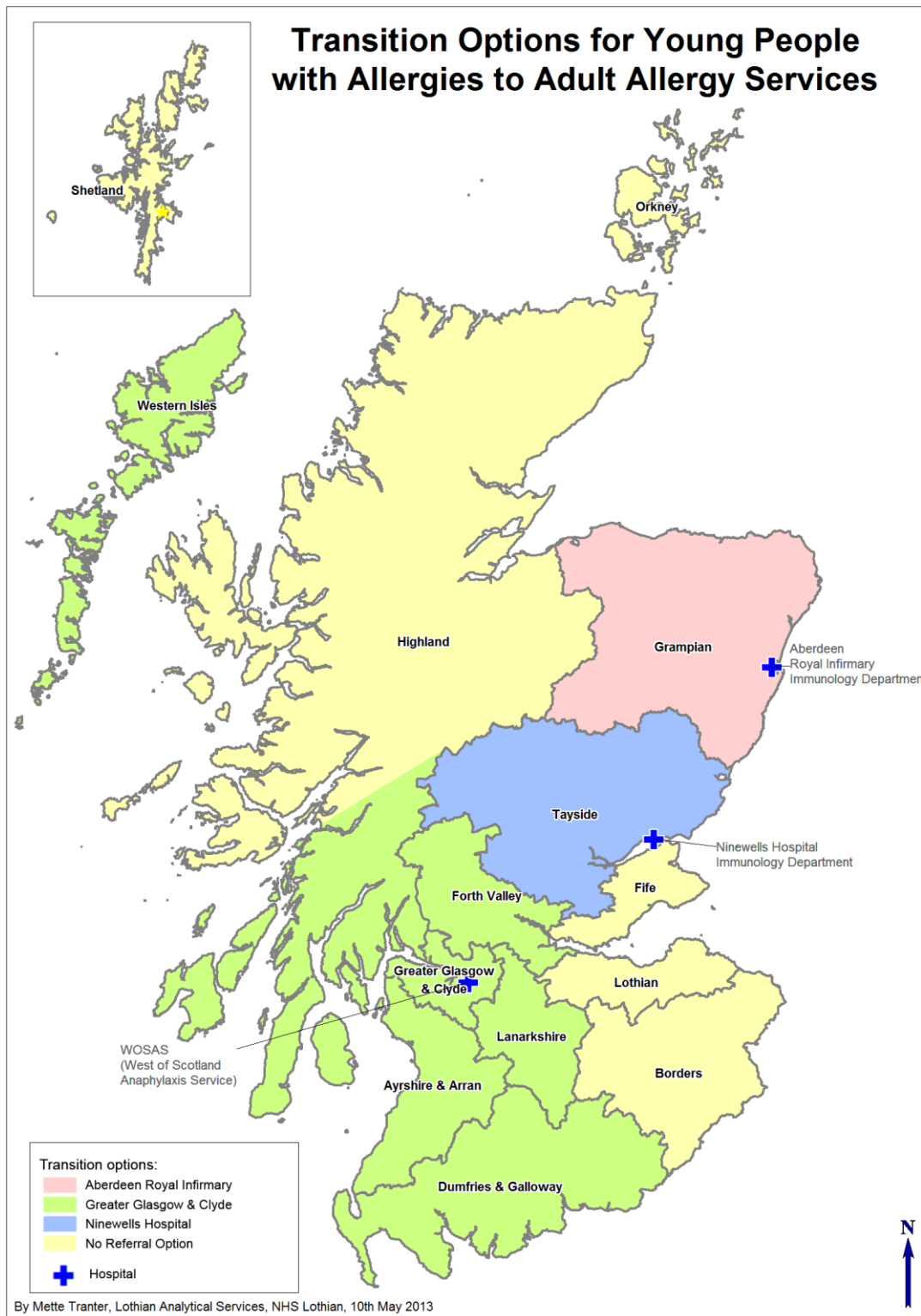
The survey also reiterated the social and emotional effects that allergy can have on a young person’s quality of life<sup>19</sup>. These findings are supported by recent research indicating that young people are at increased risk of adverse or fatal reactions and high morbidity due to their allergies<sup>13, 14, 15</sup>. Therefore increased awareness of the impact of allergy on quality of life and improved support mechanisms through clinicians and school/college staff would enable and empower young people to manage and cope with their allergies more effectively. This is further supported by a recent study by the Anaphylaxis Campaign that involved young people and found that they reported increased attendance at A&E for allergy with few having access to specialist allergy care, suggesting that support for young people with severe allergies and access to adult allergy care are inadequate<sup>16</sup>. Improving support for young people with allergies could potentially reduce the need for unscheduled care and improve the young person’s quality of life.

### **5.1 Adult allergy services in Scotland available for transition of young people**

The following lists the adult allergy services currently available, that accept young people with allergies who need to transition from paediatric services.

- NHS Greater Glasgow and Clyde: the West of Scotland Anaphylaxis Service (WOSAS) takes referrals from age 13 years upwards.

- NHS Lothian: no formal adult allergy service, but referrals are possible to a consultant dermatologist with interest in allergy or to the allergy service in Newcastle.
- NHS Tayside: the Immunology Service at Ninewells Hospital Dundee takes referrals from age 16 years upwards.
- NHS Grampian: the Immunology Service at Aberdeen Royal Infirmary takes referrals from age 16 years upwards.



## **5.2 Recommendations**

- **Increase access for young people to existing adult allergy services in Greater Glasgow & Clyde, Tayside and Grampian and develop allergy services for adults in NHS Lothian and in other health boards where the need for such services is identified.**
- **Develop pathways of care for young people with allergies, (with an initial focus on anaphylaxis and food allergy), who need to transition to adult services, linking with primary care and adult organ based specialties where appropriate.**
- **Provide allergy training for clinicians to ensure they have the skills and knowledge to treat and manage young people with allergies during their transition to adulthood.**
- **Provide education for primary care clinicians on the impact of allergy on daily living and the emotional and social wellbeing of young people.**
- **Further develop CYANS website in consultation with young people to improve information relevant to transition and access to support groups.**

## 6. Education and training

Education and training in allergy has been highlighted as an ongoing concern in various government reports over the past 10 years with undergraduate training having limited allergy content<sup>10, 11</sup> and access to post graduate training in allergy centred on the south of England. The SMASAC report 2009<sup>4</sup>, highlighted that '*many hospital clinicians have limited expertise in the diagnosis, assessment and management of allergy*' and '*some primary care staff lack the knowledge and training to provide fully effective frontline care*' and its recommendations included, '*improved access to basic training*' as well as '*enhanced training*' for more experienced staff and '*mentoring opportunities*' with specialists to enable improved support for allergy management especially in primary care. The need to develop a programme of training and education in allergy for clinicians in both primary and secondary care was also highlighted by health care professionals in the CYANS discussion sessions (see section 3).

### **6.1 Identifying current training needs**

A survey was used to gain information from across Scotland and to assess the education and training needs of clinicians currently treating and managing children and young people with allergies. The specific aims were to identify any training gaps or requirement for training in specific aspects of allergy and to capture the different training needs of clinicians in primary and secondary care. A total of 221 clinicians responded to this survey. Responses were captured from all 14 health boards in Scotland, from clinicians in primary and secondary care and a wide range of specialties relating to allergic disease.

[http://www.cyans.scot.nhs.uk/files/cyans\\_education\\_training\\_survey\\_evaluation\\_report\\_2013.pdf](http://www.cyans.scot.nhs.uk/files/cyans_education_training_survey_evaluation_report_2013.pdf)

#### **A. Training**

Over 95% of respondents are interested in further allergy training to develop their skills and allergy education/training was identified as a priority by over 74% of the respondents.

75% of respondents stated they had received training in the management of allergic disorders including undergraduate training (36%), postgraduate training(48%) and short courses(38%). Short courses or diplomas mostly related to asthma with some respondents having completed specific allergy modules. Other examples of training included attendance at conferences and study days (e.g. CYANS/SPAG annual allergy study day).

The training topics most often requested were management of allergy (77%), diagnosis of allergic conditions (62%) and guidelines and pathways (71%).

Respondents from both primary and secondary care wanted to see the training delivered as a mix of face to face sessions (45%) and e-learning (69.3%).

#### **B. Confidence to deliver care**

The education and training needs survey was also used to gauge how confident clinicians felt they were in diagnosing and managing allergies:

- Allergic conditions are seen regularly in both primary and secondary care settings, with the majority of primary care clinicians having no special interest in allergy. If clinicians in primary care do have a particular interest in allergy, it is most often in food allergy or asthma.
- Eczema and asthma were the conditions that most clinicians felt confident in providing care for and were least confident with allergic gastroenteropathy and insect venom allergy.
- Over half (53%) of respondents prescribe adrenaline auto injectors to children but nearly a third (30%) of these respondents did not feel confident to advise patients on how and when to use them.

- 72% of respondents in primary care did not feel completely confident in the appropriate selection of diagnostic tools in the detection of allergy.
- The majority of clinicians (83%) provide information on allergy, in primary care this information is given verbally and in secondary care a combination of verbal and written information is used.
- The majority of clinicians routinely require additional information on food allergy and anaphylaxis in primary care and on food allergy in secondary care.

### ***C. Impact on patient care***

It is anticipated that increased allergy education and training for primary care clinicians will ease the burden of referrals to secondary care as more allergic conditions will be adequately and efficiently addressed within primary care. This will mean that more patients with complex or difficult to manage allergies can be seen quickly and efficiently and children and their families will receive the care they need close to home.

Clinicians will be better equipped to;

- Detect allergies early, thus helping to improve quality of life and reduce emergency admissions, unnecessary treatments and prescriptions.
- Appropriately select tests for allergy diagnosis, reducing cost of unnecessary or repeat testing for allergy.
- Inform patients of their condition with access to standardised information, reducing risk of conflicting or confusing advice.

## **6.2 Recommendations**

- **Develop an education and training package for clinicians in primary care with a focus on food allergy and anaphylaxis, providing a mixture of online and face to face learning to consolidate learning and provide practical elements to training.**
- **Develop a training pack / training resource to enable clinicians with expertise in allergy to train other clinicians.**
- **Ensure protected learning time and funding to allow clinicians to develop their skills and knowledge in allergy in order to provide improved and more efficient patient care.**
- **Promote access to formal allergy training (e.g. Allergy MSc) for all interested clinicians.**

## 7. Clinical recommendations for the management of allergy

The 2009 SMASAC report outlined recommendations for improvements in allergy care in Scotland and highlighted the '*need for better promulgation of evidence based practice e.g. patient referral protocols, care pathways for children and adults and a standardised approach to clinical management through national guideline development*'.

CYANS' Models of Allergy Working Group which includes allergy specialist clinicians from a range of disciplines and professions was tasked with developing allergy management recommendations for anaphylaxis and food allergy in order to promote consistency throughout the health service. The group initially undertook a review of the existing guidelines, standards and recommendations available nationally and internationally, including the following:

- Royal College of Paediatricians and Child Health (RCPCH) pathways
- National Institute of Clinical Excellence(NICE) guidelines
- British Society of Allergy and Clinical Immunology (BSACI) (UK) guidelines
- European Academy of Allergy and Clinical immunology (EAACI) position papers
- World Allergy Organisation (WAO) position statements
- Scottish Intercollegiate Guidelines Network (SIGN) guidelines
- Local NHS board guidelines, protocols and policies

The suitability of all of the above was assessed for use within the clinical context in NHS Scotland, taking into account guidelines already in use in NHS Scotland (e.g. resuscitation guidelines for anaphylaxis). Recommendations were developed, peer reviewed and approved by the CYANS Steering Group and then made available on the CYANS web site for general clinical use.

The aim of the recommendations is to provide clarity on treatment and management options for children and young people in Scotland and provide a more consistent approach to allergy care. These recommendations will be readily accessible to clinicians in Scotland addressing the need identified in the previous sections.

### **The working group has developed the following recommendations:**

- Recommendations for the management and treatment of children and young people with anaphylaxis.  
<http://www.cyans.scot.nhs.uk/files/cyans-recommendations-2012.pdf>
- Recommendations for the treatment and management of children and young people with food allergy.  
[http://www.cyans.scot.nhs.uk/files/CYANS\\_Food\\_Allergy\\_recommendations\\_final.pdf](http://www.cyans.scot.nhs.uk/files/CYANS_Food_Allergy_recommendations_final.pdf)

### **7.1 Recommendation**

- **CYANS to deliver a series of road shows across Scotland to promote and raise awareness of the recommendations and their use in clinical practice within NHS Scotland.**

## **8. Continuous quality improvement and service planning: the CYANS allergy database**

The Healthcare Quality Strategy aims to ensure that the people of Scotland have access to high quality health care through services that are safe, effective and person centred. Key to this is the continuing scrutiny of opportunities to deliver service improvements through the delivery of optimal, evidence based care that adds value from the patients' perspective, optimises productivity and reduces unwarranted variation.

These aims can be achieved by continuous quality improvement and service planning both of which rely on current robust allergy care data, as highlighted by the SMASAC report 2009<sup>4</sup> which stated the need for the '*development of a robust system for regular collection of accurate allergy related workload data*', relevant data analysis and links across datasets '*if truly effective health service planning for allergic disease is to be achieved in Scotland*'.

CYANS has developed and is currently piloting a database for the collection of allergy data that enables the audit of current and future service provision and facilitates allergy research. An incremental approach has been taken in order to ensure that data collection would remain manageable, beginning with anaphylaxis. The National Clinical Audit System (NCAS) developed by National Information Services Group (NISG) was chosen as the platform to collect allergy data. CYANS worked with the NCAS outline for the database to create data fields for allergy, concentrating on the development of a dedicated page for collating data for anaphylaxis. Existing databases held within the NHS and internationally were reviewed to find out which systems/fields were best suited to capture the relevant data.

To enable a systematic approach to collating the data fields and in keeping with other methods of data collection already available, a proforma based on clinical history taking was developed; these fields were then mapped onto the NCAS database outline, and structured according to the proforma.

A coding structure was agreed in order to enable more effective audit of data. It was agreed that ICD 10 coding was too limited in its application and SNOMED coding was chosen as a more granular structure that will capture a wider range of information, be more versatile and have better functionality for allergy coding between primary and secondary care.

### **8.1 Pilot of CYANS database**

During the development of the CYANS database the data fields for anaphylaxis were tested by 4 clinicians working in different health boards to ensure feasibility of data collection against data fields and develop a user friendly data base. The initial feedback was very positive, with only few changes having been fed back to NISG.

### **8.2 Information Governance**

It has been necessary to ensure that CYANS establish appropriate governance mechanisms to ensure safe and secure access to confidential data, and develop patient information about the collection of data for audit and research into allergy.

### **8.3 Quality Care Indicators**

Quality care indicators (Appendix 2) have been developed to assist with quality improvement. It will be necessary to conduct an initial audit to test the validity of the quality indicators against the data collected (August 2013).

### **8.4 Next steps**

The CYANS database is live and clinicians have been identified to input data in the majority of health boards, with work ongoing to provide backfill of data in selected health boards. Work is ongoing to identify a lead clinician for each health board who will input data.



Future work involves setting up clinical audit templates for use in the long term to evaluate and monitor the efficacy of the data collected against core quality indicators and current best practice guidelines.

The CYANS database will provide:

- Robust base line data to audit service provision of allergy within Scotland.
- Ongoing data collection within each health board to enable audit of service improvements for the future.

### **8.5 Recommendations**

- **Continue the initial audit and evaluation of data on anaphylaxis collected via the allergy database in order to provide valid baseline data for allergy service provision in Scotland.**
- **Develop clinically relevant tools to aid audit of allergy data for quality improvement.**
- **Continue and increase allergy data collection, maintain and, if required, improve the CYANS allergy database.**
- **Develop further the CYANS allergy database to build in data fields for food allergy and then, resources permitting, additional allergic conditions.**
- **Continue to train clinicians on the CYANS allergy database.**

## 9. Communication and engagement with stakeholders

In order to communicate and engage effectively with all CYANS key stakeholders, CYANS has worked to develop a clear brand identity, promote and raise the profile of CYANS across Scotland, develop joint working partnerships with interested organisations, foster relationships to support or develop funding, engage with regional and national planning and NHS boards to promote awareness of specific issues related to allergy, raise awareness and gain support for educational projects and above all develop opportunities that will allow the work of CYANS to continue.

In order to enable communication with a wider audience CYANS has developed close working relationships with voluntary sector organisations involved in allergy including Asthma UK Scotland and The Anaphylaxis Campaign.

By engaging with stakeholders, CYANS has been able to address two of its important aims:

- To increase awareness of allergy and allergic conditions and the impact of these conditions on children, young people and their families
- To provide clear and consistent information on allergy across NHS Scotland.

[http://www.cyans.scot.nhs.uk/files/cyans\\_comm\\_engagement\\_strategy\\_doc.pdf](http://www.cyans.scot.nhs.uk/files/cyans_comm_engagement_strategy_doc.pdf)

### **9.1 Website**

Young people and families were keen to have online access to reliable allergy information and clinicians requested online access to information about allergy services, guidelines and pathways. The CYANS website addresses these needs and provides a readily accessible source of support for both health care users and clinicians. In keeping with the Scottish Government ethos of '*providing care that is patient centred*', CYANS has developed a website with strong input from young people, children and their parents.

The website is a growing source of reliable information and practical advice that will enable parents, children and young people to gain a better understanding of allergic disease and provide support for those living with allergy. This will support compliance with allergy management recommendations by clinicians and, where appropriate, empower patients to self-manage their allergies, as well as providing a platform for patients and their families to raise their concerns or show their appreciation of the allergy care they receive.

<http://www.cyans.scot.nhs.uk/>

### **9.2 Recommendations**

- **Continue to communicate and engage with all key stakeholders involved in CYANS.**
- **Maintain current relationships with stakeholders by sending regular newsletter to all registered contacts, displaying posters and postcards to promote CYANS and informing health care users about its work.**
- **Maintain and further develop the CYANS website**

## **10. The CYANS model of allergy care for Scotland**

### **10.1 CYANS recommendations for the further development of allergy services in Scotland**

Given the high numbers of children and young people suffering from allergic conditions which in the majority of cases are not severe and are straight forward to diagnose and manage, it is inevitable that a major part of allergy care will have to be provided in the community. The smaller, but still considerable, numbers of children with severe, multiple or complex allergies require access to specialised allergy expertise in secondary and tertiary care.

Therefore, to provide and further develop equitable, accessible, high quality allergy service provision, as close to home as possible, to children and young people across Scotland, CYANS recommends a model of allergy care that will provide:

- Easily accessible competent diagnosis, treatment and management of frequent allergic conditions in primary care.
- Access to state-of-the-art secondary and tertiary allergy care when required.
- Evidence based allergy advice to support patient self-management where appropriate.

The basis for such high quality allergy care is a high level of knowledge and skills in the diagnosis and management of allergy in primary care, the availability of a multidisciplinary secondary care allergy service in each health board and support of both primary and secondary allergy care provision by the existing specialised tertiary allergy services. National guidelines, patient pathways with clear referral criteria, (such as those developed by the Royal College of Paediatrics and Child Health (RCPCH), and mentorship and clinical allergy support networks will enable the integration of the different levels of allergy services and this will be supported further by the collaboration of clinicians in CYANS as an NMCN. For quality improvement, planning and further development it will be essential to obtain comprehensive and reliable data on the incidence and prevalence of allergic conditions, patterns of health care usage by patients and the type and quality of care delivered.

As outlined in preceding sections, CYANS' work over the past 2 years has established major information needs for patients and families, allergy education and training needs for clinicians and development needs and gaps in current allergy care provision for children and young people in Scotland. All of these will have to be addressed before the high quality allergy care as outlined above is achieved across Scotland. This has resulted in the recommendations set out below.

#### **A. Patient support and self-management of allergy**

To increase patient support and enable self-management the following is required:

- Evidence based allergy information that is easily accessible for patients and their families in a format appropriate to their age and understanding. This should include information on 'growing-up and relationships' for young people with allergy, and could be provided via the CYANS web site.
- Resources to educate the wider family and friends of allergy patients (especially in teenagers) to enable them to help prevent and recognise allergic reactions and deliver treatment promptly, including recipes and food lists for food allergy.
- Access to allergy advice when needed including 'out of hours' support.

- Allergy education and training for key support staff for children including health care professionals, school staff including nursery, and staff involved in 'out of school' activities.
- Collaboration between health and education to support allergy education within the school setting to enable greater understanding of allergy amongst peers.
- Collaboration between health and the voluntary sector to enhance allergy awareness in the food, catering, travel and holiday industries and in the general public.
- Local patient support groups.

**B. Enable easily accessible and competent diagnosis and management of frequent allergic conditions in primary care**

- Improve allergy education and training opportunities for primary care clinicians to ensure they have the necessary skills to recognise, treat and manage allergic conditions, concentrating on food allergy and anaphylaxis.
- Develop and make available an education and training package for clinicians in primary care (such as the one piloted by CYANS) with a focus on food allergy and anaphylaxis, providing a mixture of online and face to face learning to consolidate learning and provide practical elements to training.
- Develop education mentorship arrangements for primary care clinicians.
- Strengthen allergy care provision in the community.
- Encourage primary care clinicians to develop an allergy interest.
- Enable cross referral within primary care to clinicians with allergy expertise.
- Develop a 'clinical allergy support network' through which clinicians with allergy expertise enable primary care clinicians to provide high quality allergy care locally.
- Provide clear clinical pathways to help clinicians identify the allergy resources available in their given health board.
- Fund additional specialist allergy nursing and dietetic support in primary care to allow improved access to multidisciplinary support for allergy patients.

**C. Optimise care for complex and severe allergy in secondary and tertiary care.**

- Ensure that each health board has an allergy service led by an identified paediatric consultant or clinician with appropriate allergy training, which is equipped to deliver multidisciplinary allergy care, including dietetic support when required.
- Develop multidisciplinary 'one stop' allergy clinics in each health board that provides an allergy service.
- Provide access to a dietician with adequate experience in food allergy management in each health board.
- Provide formal training opportunities and ensure funding and protected time to enable paediatric consultants, nurses and dieticians with an interest in allergy to develop the appropriate skills.
- Enable clinicians specialised in allergy to provide mentorship and allergy service support to less specialised colleagues in secondary and primary care.
- Develop information resources for secondary care clinicians to ensure a consistent approach to information giving to patients and families.
- Provide a dedicated specialist allergy nurse within each health board, to provide a link between primary and secondary care.
- Enable the provision of immunotherapy services in tertiary allergy centres.
- Provide transition arrangements and access to clinicians with allergy expertise, beyond primary care, for young people with complex and severe allergies, who have outgrown paediatric services and are 'transitioning' to adult care.

#### **D. Quality improvement and service planning**

- Continue allergy data collection and maintain the CYANS allergy data base in order to provide valid baseline data for allergy service provision in Scotland.
- Develop clinically relevant tools to aid data audit for quality improvement of allergy care.
- Develop the CYANS allergy database further to enable the collection of information on food allergy and then, resources permitting, additional allergic conditions.
- Continue to train clinicians on the CYANS allergy database.

#### **E. Enable the continuation of CYANS as a National Managed Clinical Network**

CYANS' successful work during its pan-Scotland project phase indicates that, as a model for service development based on the collaboration between a wide range of stakeholders, CYANS will be the most effective mechanism available to ensure that the above recommendations for improvements to allergy care for children and young people across Scotland can be achieved. To this end CYANS will need to continue working as an NMCN in the longer term.

[http://www.cyans.scot.nhs.uk/files/cyans\\_interim\\_report\\_ndp\\_mon\\_feb13.pdf](http://www.cyans.scot.nhs.uk/files/cyans_interim_report_ndp_mon_feb13.pdf)

It will only be through an NMCN that equitable access to allergy education and training, educational allergy mentorship and an "allergy service support network" can be provided to a wide range of clinicians across Scotland, enabling them to obtain the knowledge and skills required and to provide high quality allergy care in primary and secondary care.

In addition, quality improvement in allergy has to be supported by an NMCN to ensure that allergy care data is collected in a standardised format throughout Scotland, audited to identify any shortcomings and that recommendations for improvement are implemented, enabling best practice in allergy across Scotland.

Furthermore, the very successful programme of engagement of young people and parents of children with allergies from across Scotland which enables them to contribute their views and aspirations for the improvement and development of allergy services, and the provision of allergy information to service users through the CYANS web site will require ongoing support from an NMCN.

## **10.2 Key recommendations**

- **Improve the standard of knowledge of allergy and provide education and training for all clinicians working with children and young people with allergies with an initial focus on primary care.**
- **Provide in all health boards a dedicated allergy service or identified clinician adequately trained in allergy to take allergy referrals in secondary care and to deliver allergy care as close to home as possible.**
- **Develop clear referral pathways through primary, secondary and tertiary care to clarify access to allergy services, including transition arrangements to adult services.**
- **Increase allergy awareness amongst health care professionals and education staff to enable them to respond appropriately to allergic reactions and to acknowledge and lessen the impact that allergy can have on the patient and their family.**
- **Develop and make easily accessible appropriate evidence based allergy information for all health care professionals to standardise the quality and level of information given to patients and their families.**
- **Continue to maintain and develop the CYANS allergy database and ensure data collection to aid planning of allergy service provision, quality improvement and audit, and research into allergy with an initial focus on anaphylaxis and food allergy.**
- **Designate CYANS as a NMCN to facilitate implementation of these recommendations and to develop CYANS as a central point of contact for information, guidance and resources for allergy in Scotland.**

## 11. CYANS progress against previously identified issues in allergy care in line with Scottish Government objectives

Several reports have been commissioned to look at what can be done to improve allergy care across the UK, highlighting a range of barriers to improvements which include a lack of recognition of the need for allergy services, especially from key commissioners, under resourcing of staff, and poor communication and lone working amongst allergy health care professionals.

In Scotland the SMASAC report of 2009 identified a number of key barriers to the delivery of allergy care in Scotland, and CYANS has been working to address some of these issues over the last two years including:

- **Need for improved data collection and audit as tools to better healthcare planning and delivery**  
CYANS has developed an allergy database, initially with a focus on severe allergy and anaphylaxis. CYANS plans to extend data collection to capture food allergy and, future resources permitting, the wider field of allergy.
- **Insufficient numbers of adequately trained healthcare professionals in allergy**  
CYANS is working to address this issue by developing an allergy educational package, that has recently been piloted successfully and which will hopefully receive backing and funding to be made available to all interested clinicians in primary care.
- **A fragmented service without clear linkage between primary, secondary and tertiary allergy care**  
CYANS has worked to develop communication and engagement within the network across all allergy service providers, completed work to map current service provision across Scotland and begun the process of developing a mentoring and allergy care support network to support clinicians in delivering high quality allergy care across primary, secondary and tertiary care boundaries.
- **Need for better promulgation of evidence-based practice**  
CYANS has made clinical recommendations for the diagnosis and management of both anaphylaxis and food allergy and is in the process of developing a food allergy resource pack for clinicians to ensure a consistent and evidence based approach to the diagnosis and management of children and young people with allergy across Scotland. Care pathways across services including transition pathways are under development.
- **Lack of accessible information for patients, carers, and the general public to support understanding and self-management of allergic disease.**  
CYAN is working to develop information for the general public. Working with children, young people and their families CYANS is finding out what information they need and in what format they would like to access the information, which can be made available via the CYANS website.

CYANS' work closely aligns with the Scottish Government National Performance Framework and addresses the following strategic objectives to ensure that:

- Children have the best start in life and are ready to succeed
- We live longer, healthier lives.
- Public services are high quality, continually improving, efficient and responsive to local people's needs.

In relation to the following national indicators CYANS is working towards:

**A. Reducing emergency admissions**

Improving education and access to information for clinicians, especially in primary care, will facilitate access to appropriate allergy care for children, young people and their families therefore potentially reducing A&E attendances and repeat admissions for allergic emergencies.

**B. Improving quality of health care experiences**

CYANS has developed a national allergy database to aid quality improvement of allergy care, service development, and research into allergic conditions in Scotland with an initial focus on anaphylaxis and food allergy. CYANS is working to improve access to evidence based information for clinicians and the general public. It aims to improve standards of clinical care through education and training and the development of mentoring networks for clinicians. It is anticipated that improved access to and standards of care, will reduce the morbidity associated with allergy and improve quality of life for patients and their families.

**C. Improving people's experiences of allergy care**

Through allergy training, particularly in primary care, and through the creation of a clinical allergy service support network CYANS will enable clinicians to treat more children and young people locally, as close to home as possible.

CYANS has worked with children and young people and families to find out their perceptions of allergy care and aspirations for future service provision. This will enable CYANS to deliver improvements to allergy care based on public feedback and research.

**D. Improving knowledge transfer from research activity in universities**

CYANS has established close working links with higher education institutes to ensure that up-to-date evidence based information and research is available to support the work of the network. CYANS comprises a mix of clinicians and academics interested in allergy which enables a close working partnership between research and developments in allergy care and future plans for service delivery. This collaborative approach is particularly evident in the development of the CYANS Allergy database and CYANS' educational events.



## 12. Glossary of terminology

- **Adrenalin auto-injector** - a device used to deliver a measured dose of adrenaline
- **Anaphylaxis** – a potentially life threatening acute allergic reaction, affecting multiple systems in the body, involving the airways, breathing or the circulation.
- **Complex multiple allergies** –the combination of several allergic condition, including asthma, eczema, allergic rhinitis, food allergy, and anaphylaxis, that require treatment.
- **Delayed allergic reaction (non IgE mediated)** – an allergic reaction that takes longer to develop, usually 4-8 hours after exposure to the allergen.
- **Immediate allergic reaction (IgE Mediated)** – an allergic reaction that happens quickly, usually within minutes to 2 hours of exposure to the allergen. Symptoms can vary from a mild rash to life threatening anaphylaxis.
- **Multi-disciplinary care** – care that is delivered and coordinated by all professionals involved in the patients care, this can include paediatrician, nurse, dietician, organ based specialist and others.
- **NMCN** – National Managed Clinical Network - enabling health care professionals, patients and their families and all organisations with an interest in the specific health condition to work together, across geographical boundaries, to improve health service provision across Scotland.
- **Primary Care** – refers to health care delivered within health centres and general practice, care is often delivered by the general practitioner (GP) or a nurse. The centre of care is usually close to the patients' home.
- **Secondary care** – refers to health care delivered within a hospital setting.
- **Stakeholders** –persons or organisations who have an interest or concern in allergy services, this can include clinicians, patients and their families and voluntary organisations.
- **Tertiary care** – refers to specialised health care service with higher levels of expertise and services than district general hospitals, these hospitals have the capacity to take referrals from other health boards.
- **Transition service** – the process of preparing a young person to move from paediatric services onto adult services for their health condition.
- **Voluntary Sector** – non-profit or charitable organisations involved in working with the public.

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## Appendix 1

### CYANS Work Plan for 2013-2014

Action	Outcome	Date
Develop and deliver road shows to health boards across Scotland to assist with implementation of recommendations	Improved allergy service provision for patients and families Clear referral pathways and pathways of care	Ongoing throughout 2013/ 2014
Evaluate efficacy of the allergy education pilot project for primary care	Development of an allergy education and training programme for clinicians in primary care	June - Sept 2013
Delivery of allergy education for primary care	Allergy training for primary care clinicians available locally in all health boards	Oct 2013 - June 2014
Develop, monitor and evaluate mentor support for clinicians	Education and support made available to clinicians as locally as possible	Ongoing throughout 2013 /14
Develop, monitor and evaluate clinical allergy support network	Clinicians will be empowered to provide high quality allergy care locally.	Ongoing throughout 2013 /14
Organise and deliver service user workshops across Scotland	Service users can feedback to CYANS the impact of its work on the services they use	Spring 2014
Audit and evaluate data collected on CYANS - allergy database and develop clinically relevant audit tools for quality improvement	To provide valid baseline data and enable audit of allergy service provision in Scotland	Ongoing throughout 2013/ 14
Develop CYANS - Allergy database to collect information on food allergy	Effective method of data collection on food allergy and provision of base line data for Scotland	Data collection from November 2013, initial audit estimated May/June 2014
Develop practical resource package for food allergy	Resource will equip all primary care clinicians and general paediatricians with resources to treat and manage straightforward food allergy.	Throughout 2013/14

## **Appendix 2**

### **CYANS Care Quality Indicators for Anaphylaxis**

- % of children and young people with suspected or confirmed anaphylaxis who have been referred for specialist assessment.
- % of children and young people with suspected or confirmed anaphylaxis who have had a diagnosis confirmed or refuted.
- % of children and young people with suspected or confirmed anaphylaxis who have had triggers identified or excluded.
- % of children and young people who have been prescribed an adrenaline auto injector at the correct dose.
- % of children and young people diagnosed with confirmed or suspected anaphylaxis that are reviewed annually by a specialist clinician.
- % of children & young people who have been given a management plan on discharge after a suspected anaphylaxis event.





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