

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND CHAPTER 11: PAEDIATRIC ALLERGY



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11.0 INTRODUCTION

Asthma and eczema are the most common chronic conditions of childhood, and the spectrum of atopic conditions (which also include rhinitis and food allergy) affect 40% of the population. Internationally, there has been a significant rise in the prevalence of food allergy which currently stands at 5-10%. Four percent of Irish children (approximately 28,600 based on 2011 census data) have all three major conditions, representing a major family and healthcare burden. Food allergy, proven by food challenge, is present in 4% of Irish two year olds. Nationally, 20,000 children have peanut allergy. Incorrectly managed multiple food allergy is associated with nutritional deficiency, risk of anaphylaxis and fatality and social isolation. Despite these staggering figures and risks, paediatric allergy appears to be the best kept secret in paediatrics.

The traditional model of organ-focused care of the individual conditions is well established in Ireland, whereas allergy-focused care places the child at the centre of the clinical care pathway. The Finnish Allergy Programme (2008-18) has six main goals:

- 1. Prevent the development of allergic symptoms;
- 2. Increase tolerance against allergens;
- 3. Improve diagnostics;
- 4. Decrease work-related allergies;
- 5. Allocate resources to manage and prevent exacerbations of severe allergies (immunotherapy)
- 6. Decrease costs caused by allergic diseases.

These goals are similar to those of the Irish Food Allergy Network (IFAN).

11.1 CURRENT SERVICE PROVISION

To date, there has been no strategy to develop allergy services in Ireland. Paediatric Allery is the most under developed of all paediatric services. Most food allergic children have never been seen by a specialist.

Allergy of all forms can be predominantly managed in primary and secondary care, but the knowledge base of General Practitioners (GP) remains low. Patients may be engaged in multiple services for the management of asthma, eczema, rhinitis and food allergy. Care delivery is mostly ambulatory, with day case food and drug challenges and testing in high demand. In larger centres, allergy consults may be required, e.g. antibiotic allergy testing and desensitisation in cystic fibrosis patients.

Professor Jonathan Hourihane established the first paediatric allergy service in Cork University Hospital, and this receives referrals from all over the country. Dr. Aideen Byrne was appointed in Dublin in 2013. Dr. John Fitzsimons (Drogheda), Dr. Edina Moylett (Galway) and Dr. Imelda Lambert (Mullingar) all have special interest in allergy but do not have dedicated clinical service time. Cork has been providing all tertiary care services nationally, and most secondary care services.

Cork

Allergy service staffing in Cork University Hospital comprises 0.5WTE consultant, 1.0WTE clinical nurse specialists (CNS) and oWTE dietitian. Outpatient clinics are held weekly with 450 new patients seen annually (the majority of referrals are from primary care). Waiting time for a first routine appointment is 15 months, and for food challenge is over 3 years. Each year, 1000 patients are skin tested, 150 food challenges are performed, and 10-12 new episodes of inhalant or insect sting allergen-specific immunotherapy are initiated. Priority is given to anaphylaxis followed by infants aged 6-12 months. There are 100 urgent cases seen annually in the day unit.

Dublin

Our Lady's Children's Hospital Crumlin (Crumlin):

Currently there is 0.6WTE consultant in allergy, 1WTE CNS and 0.5WTE dietitian. Outpatient clinics are held twice a week and there is also a weekly joint allergy dermatology clinic and a small urgent access clinic. All clinics are equipped with a dietetic, skin testing and education service. The waiting list is rapidly increasing for routine patients and will soon be greater than 12 months. The Allergy Service needs to increase its capacity to see new patients by 50% in order to manage the huge volume of referrals and to meet targets.

200 food challenges and 30 non-food challenges were performed in the first year of the service. The food challenge service is in a rapid growth phase as many of the children being seen in clinic have numerous long term food exclusions. At least ½ of the children on the waiting list will require a further food challenge and so it is anticipated that at current operating levels, the waiting list will grow a further 50% in the next year. Already waiting list times are unacceptable especially for young children with multiple food exclusions.

Tallaght Hospital:

There is 0.3WTE consultant in allergy with 0.5WTE CNS. There is a weekly clinic and a weekly urgent access clinic. Waiting time for routine patients is 14 months. All clinic's are equipped with a skin testing and education service. There is no dedicated dietetic support. The service also provides a food challenge service: approx. 3 / week. Another paediatrician also sees some food allergic children with the support of a dietitian.

Children's University Hospital, Temple Street (Temple Street):

At the time of writing there is no established allergy service at Temple Street, but a secondary outpatient service with skin testing facilities (supervised by Immunologist Dr. Ronan Leahy) is being considered to deal with routine referrals from GPs and EDs. This will be done in conjunction with the service in Crumlin with standardised training of support staff by Dr. Aideen Byrne.

Drogheda

Less than 0.1WTE consultant has been allocated to provide a regional allergy service in Louth, Meath, Cavan and Monaghan since 2011. Bimonthly clinics are held, with the majority of patients attending with suspected food allergy. In 2012, 262 new patients were seen, and the waiting time for a new appointment is over 12 months. Galway

Less than 0.1WTE consultant with a special interest in allergy

Mullingar

Less than 0.1WTE consultant with a special interest in allergy.

Patients and families seek allergy services for two main reasons:

- 1. To get diagnostic support for reactions known (or strongly suspected) to be due to an exposure to an allergen ("This is allergy")
- 2. To be assessed for symptoms that they or others feel might be due to an allergy ("Is this allergy?")

In the first scenario, there may be anaphylaxis with presentation to the emergency department, or families may report only more minor reactions to their GP. In these situations, there is considerable potential for inappropriate or incorrect treatment plans being initiated prior to referral to secondary outpatient services. In the second scenario, most families will be reassured after an allergy-focused clinical history with or without diagnostic testing. In 75% of new cases seen in Cork, the diet is broadened after the first consultation rather than restricted further. Frequent review is only required for infants who may need to access expert dietetic and nursing support, with most children rapidly moving to annual review. This interval may even be lengthened after school entry as most infant allergies will have resolved by then and persistent allergies will usually be static.

Diagnostic food and drug challenges require day case attendance and should only be performed by experienced staff. They are central to an allergy diagnosis and also in food and medication reintroduction. Only the most essential challenges are currently performed, which results in unnecessary dietary restrictions and drug avoidances. While challenges are not difficult they do take time, and emergency medications and other modalities of care may be required. In Cork, 3% of positive food challenges have required adrenaline in comparison to 11% in international data series.

11.2 PROPOSED MODEL OF CARE

The vision is of an integrated allergy service that ensures:

- · Integrated care for all aspects of allergic disease, eczema, asthma, food allergy and rhinitis
- Early diagnosis of childhood food allergy, and the provision of comprehensive evidence-based advice on management in a consistent manner nationally
- Safety and health of children with food allergy in their daily lives, through minimising nutritional deficiencies, anxiety and/or anaphylactic reactions
- $\bullet \quad \hbox{Timely access to world class standard tertiary allergy services for those that require them}\\$
- · Regular follow up appointments to provide education for patients with life long allergies
- · Ongoing monitoring of service provision to predict future needs

The proposed model of care crosses all care settings:

PRIMARY CARE	RIMARY CARE Simple milk, egg and peanut allergy, eczema, rhinitis and asthma can be		
	managed in primary care with the emphasis on a focused allergy history and		
	simple, justified exclusions in the diet; asthma care, including pulmonary/nasal		
	inhaler technique and competence; and initiation and maintenance of sublingual		
	allergen immunotherapy for grass pollen allergy.		
	If significant dietetic input is required, this may be accessed through community		
	nutrition and dietetic services but is more likely to be realised in secondary care.		

SECONDARY CARE

Allergy should be a core activity of all general paediatricians.

Paediatricians should be able to manage patients with prior anaphylaxis, and develop and manage care plans for patients with significant eczema, allergic rhinitis and asthma as component parts of their allergic disease. They should also be able to coordinate appropriate allergy-focused diagnostics (rather than indiscriminate panel testing) using skin testing and IgE specific blood testing in adherence with national and European guidelines.

TERTIARY CARE

Both tertiary units in Cork and Dublin require considerably more resources committed, including CNSs and dietitians, as outreach to other centres and nurse-led clinics are not possible within the current resource allocation. Four full time tertiary allergic specialists are required (2 in Cork and 2 in Dublin) and they should deal with idiopathic anaphylaxis, multiple food allergies, and eosinophilic oesophagitis (access to upper gastrointestinal (GI) endoscopy required). Clinical psychology support is also required.

Allergy services should continue to grow in Dublin, Cork and Galway and Drogeda. The Cork allergy unit will provide support to Cork, Kerry, Waterford and South Tipperary, with the Galway unit potentially serving Galway, Mayo and Sligo. Other regional centres require the development of an allergy service such as Limerick and Kilkenny. Patients in the midlands and north east should have links to the Dublin service. While Dublin services are currently fragmented across three sites, it is the goal that this service will function as a virtual unit with standardised training packages and standard operating procedures (SOP), interaction between staff at all levels in each centre, and easy movement of patients between sites according to availability of services required.

Currently there is minimal transition to adult services due to a scarcity of adult allergy services for adults. Adult allergy care is largely delivered in Dublin and Galway by consultant immunologists. Inhalant allergies often persist into adulthood, and referral to allergy-aware respiratory services will be required locally.

11.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

11.3.1 Staffing

The service will be multidisciplinary with consultant paediatricians with a special interest in allergy, CNSs, dietitians and clinical psychology. There is a requirement for more posts in paediatric allergy. Current UK guidelines recommend that a minimum of two full time consultant allergists are required to provide a quality specialist allergy service. At this time, tertiary services in both Cork and Dublin are provided by single consultants. Two additional full time consultant posts are required within the current specialist services. There is an urgent need to appoint paediatricians with an interest in allergy in multiple regional hospitals to treat and support patients locally and to reduce the burden on the tertiary services. In addition, there is also a requirement for increased dietetic services in primary, secondary and tertiary care. More allergy CNS posts are required to facilitate the development of nurse-led review clinics and regional food challenge services. In the community, an area medical officer with responsibility for allergy in the community could coordinate education of public health nurses, GPs and teachers.

Tertiary Centres (Cork and Dublin)

At present Dublin allergy is spread across 2 centres but for the purpose of this document should be considered as 1 entity.

Staff Category	Current (WTE)	Proposed (WTE)
Consultant Allergist	1/centre	2/centre
Paediatrician with an interest	o in Dublin	1/centre
in allergy	1 in Cork	
Specialist Registrar	1/centre	2/centre
SHO	o in Dublin 1 in Cork	2/centre
Specialty trained nurses	0	2/centre
Advance Nurse Practitioner	0	1/centre
Clinical Nurse Specialist	Cork 1.0 Dublin: 1.5	3/centre
Dietitian	0.5 in Dublin	Cork: 2 Dublin: 3
Psychologist	0	1/centre

Regional Centres

Development of at least 6 regional centres with adequate staffing is envisaged. Some would require greater staffing numbers.

Staff Category	Proposed (WTE)
Consultant with an interest in allergy	0.25-05.WTE
Clinical Nurse Specialist	0.5-1 WTE
Specialty trained nurse	0.25-0.5 WTE
Dietitian	0.25-0.5WTE

11.3.2 Other Resources

In addition, adequate access to immunology laboratory services is required, and outpatient and day case space more so than inpatient beds. Dedicated administration support is essential for managing referrals and the efficient and effective use of outpatient clinic time, as well as maintaining a register of food allergic patients.

11.3.3 Education and Training

There is a significant need to educate healthcare professionals at all levels about allergy. Undergraduate training of doctors and other healthcare professionals lacks a focus on comprehensive allergy management. With the development of IFAN, both the public and those working in healthcare have access to evidence-based statements which counteract the vast amounts of false information that is in the public domain. The IFAN website is a national portal for allergy education, and education sessions have been provided across the country with extremely positive feedback. Ongoing support from all health sector leads is required to ensure its ongoing success.

Currently, the most comprehensive and accessible training for those wishing to develop their expertise in allergy is in the United Kingdom. The Cork service has also provided practical training to the developing centre in

Dublin. Standards of education should be developed for those paediatricians who want to practice allergy. The development of a rotation system for junior doctors – senior house officers (SHOs) and registrars – through the tertiary centres in Cork and Dublin will also be a key opportunity to disseminate information to this group. In addition, regular case conferences and clinical meetings between all centres will be important to maintain academic standards and allow for exposure of junior doctors to complex allergy cases.

11.4 PROGRAMME METRICS AND EVALUATION

There are a number of process and outcome measures that should be monitored:

11.4.1 Waiting Times

- Waiting times for new referrals stratified by allergy centre, origin of referral (GP or paediatrician), age, history of anaphylaxis
- Waiting times for food challenges, possibly by allergen (cows milk, peanut, egg etc.)
- Time between diagnosis and referral to dietitian, waiting times for new dietetic appointment in hospital and community

11.4.2 Activity and Clinical Outcomes

- · Numbers of patients receiving sublingual immunotherapy by centre
- Food challenges: numbers, outcomes, severity of reactions
- Drug challenges: numbers, outcomes, severity of reactions
- Desensitisations: numbers, outcomes, severity of reactions
- · Central database of patients with adrenaline autoinjectors
- Success/appropriateness of adrenaline pen education
 - Patients prescribed autoinjectors outside of allergy clinics
 - Patients prescribed autoinjectors in allergy clinics
- ED attendances
 - Numbers with anaphylaxis
 - Attendances per patient
 - Attendances of those previously seen in allergy clinics
- GP attendances
 - Attendances pre- and post-allergy clinic review

11.4.3 Patient Outcomes

- Compliance with sublingual immunotherapy
- Quality of life
- Identification and monitoring of vulnerable cohorts (e.g. foreign nationals living in Ireland)

11.5 KEY RECOMMENDATIONS

- The proposed national model of care for allergy is that of an integrated service crossing all care settings, with clear roles for primary, secondary and tertiary care.
- Additional staffing resources are required to facilitate development of the service.
- · There is a significant need to educate healthcare professionals at all levels about allergy.

11.6 ABBREVIATIONS

CNS Clinical Nurse Specialist ED **Emergency Department** General Practitioner GP IFAN Irish Food Allergy Network National Children's Hospital (within AMNCH) NCH Senior House Officer SHO SOP Standard Operating Procedure WTE Whole Time Equivalent

11.7 REFERENCES

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