


# Parliamentary inquiry into allergies and anaphylaxis

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A submission from the National Allergy Strategy



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## About the National Allergy Strategy

The National Allergy Strategy is a partnership between the Australasian Society of Clinical Immunology and Allergy (ASCI) and Allergy & Anaphylaxis Australia, the leading medical and patient support organisations in Australia. The National Allergy Strategy document was developed with key stakeholder organisations and provides an overarching framework for a national response to the rise in allergic diseases. It identifies the most effective ways to:

- Address allergic disease as a chronic disease and manage it with a public health approach;
- Provide an effective and coordinated plan to guide future actions to optimise the management of allergic diseases in Australia; and
- Improve the health and quality of life of people with allergic diseases, their carers and the community.

For more information about the National Allergy Strategy or to download the document, visit:

[www.nationalallergystrategy.org.au](http://www.nationalallergystrategy.org.au)

## About this submission

Thank you for the opportunity to provide a submission for the parliamentary inquiry into allergy and anaphylaxis.

The National Allergy Strategy submission provides reference to published information where it exists. All other information is based on stakeholder engagement undertaken as part of National Allergy Strategy projects. Where appropriate, proposed solutions have been included.

The National Allergy Strategy is currently scoping a shared care model for allergy that is funded by the Australian Government Department of Health. The final scoping report for this project will be submitted to the Health Department in mid-December 2019. This report cannot be included in a public submission. Further to this, the National Allergy Strategy has also undertaken a scoping project for drug allergy and report including recommendations has been submitted to the Australian Government Department of Health. This report also, cannot be included in a public submission. However, information obtained by these projects are likely to be of interest to the parliamentary inquiry. If the committee overseeing this inquiry wishes to view these reports, the National Allergy Strategy Manager will seek permission from the Department of Health to release the reports to the committee.

This primary submission (Part 1) provides a summary of key issues that impact on people who live with allergies and includes proposed solutions as to how to improve the health and quality of life of these Australians. It is accompanied by an additional document (Part 2) which is a detailed response to each Term of Reference with links to scientific evidence where available. Part 2 is intended as a reference source if further information is required.

Our proposed solutions are put to the committee in order to highlight areas where we feel either endorsement or funding from the federal government would best help to achieve a future picture of success.

This submission has been made on behalf of and in consultation with, the National Allergy Strategy Steering Committee and Project Leads. Special thanks to the submission working group – Dr Preeti Joshi, Ms Maria Said, Ms Sandra Vale, Clin A/Prof Richard Loh, Prof Connie Katelaris, Prof Michaela Lucas, Dr Wendy Norton and Ms Heather Roberts.

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## About allergies and anaphylaxis

- Allergic diseases are amongst the fastest growing chronic disease and public health issues in Australia, currently affecting more than 4 million Australians.
- Allergic diseases include food, insect and drug allergies (including life-threatening severe allergic reactions called anaphylaxis), allergic asthma, allergic rhinoconjunctivitis (hay fever) and eczema (atopic dermatitis).
- Further increasing the medical and financial burden, several allergic diseases can commonly occur in the same individual and because the tendency to develop allergic disease (atopy) is genetic, more than one person in a family likely has it.
- Allergic diseases vary in severity and complexity.
- Allergies to food, drugs, insects, ticks and latex can also range from mild symptoms to life threatening allergic reactions (anaphylaxis) and nutritional compromise, particularly if the individual has multiple food allergies.
- The rapid and continuing increase in the prevalence and impact of allergic diseases on the health system and the quality of life of patients and carers, requires an urgent coordinated response.

## **PART 1: Primary submission (Issues 1-8)**

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### **1. Access to quality care for individuals with all allergic diseases is inequitable, and in many cases, inadequate. This is particularly the case in rural settings.**

Access to appropriate care is often delayed with long waiting times to see the relevant medical specialist/s and has resulted in patients receiving inappropriate advice from alternative/unorthodox health practitioners. Absence of appropriate care carries a significant risk of serious adverse events and increases healthcare encounters and associated costs as well as the use of unproven therapies.

Wait times for food challenges in public hospitals are unacceptably long and as there are very few safe options available in the private setting. Food challenges are a clinically essential tool to either confirm that an individual has “outgrown” an allergy or in more complicated cases, to confirm a diagnosis. They are time consuming and the severity of allergic reactions can be unpredictable, so inpatient monitoring for some is essential.

Skin prick testing (SPT) is a fundamental test in diagnosing allergies. Ordering SPT reagents is very time consuming and complicated.

#### **Proposed solutions:**

- Shared care model for all allergic conditions:
  - Fund the recommendations of the National Allergy Strategy shared care model scoping report. The draft or final report can be provided to the parliamentary inquiry committee upon request providing approval is granted by the Department of Health.
  - Implementing the recommendations of this shared care model scoping project would address many of the current access to care and quality of care issues.
- Develop and implement a national anaphylaxis Clinical Care Standard by the Australian Commission on Safety and Quality in Health Care:
  - Clinical Care Standards require adherence and monitoring (as opposed to a guideline).
  - An anaphylaxis Clinical Care Standard has the potential to standardise clinical practice regarding anaphylaxis management in hospitals and across paramedic services Australia-wide.
- Medicare Benefits Schedule (MBS) item number for food challenges:
  - Federal government support for the ASCIA application for a new MBS item number for food allergen challenges. The item number application is carefully considered to minimise its use so that it is applied only to those with well defined clinical characteristics. The aim would be to significantly reduce public hospital wait times and allow for safe and timely food challenges.
- Increased funding for national patient support organisations:
  - Additional federal government funding for reputable national patient support organisations with medical advisory boards (e.g. Allergy & Anaphylaxis Australia) to ensure sustainability and growth.
- Improved access to skin prick testing reagents:
  - Recognition of ASCIA by the Therapeutics Goods Administration (TGA) as an endorsing body for clinical immunology/allergy specialists to be authorised prescribers of SPT reagents.
  - Simplification of the TGA Special Access Scheme (SAS) applications for SPT reagents.

### **2. The cost of treatment is largely unrecognised and prohibitive.**

Medications for managing allergic diseases are expensive to the individual and families (who often have more than one allergic disease) and as a result, many cannot afford to either start or continue treatments.

Management of severe eczema includes wet dressings (whole body bandages), liberal and frequent (twice daily) use of moisturisers to the whole body and prescription-based medication. Application of all the required treatments is time consuming and labour intensive.

Besides the cost of emergency medication, people with multiple food allergies need to buy special, more expensive foods and often spend disproportionate amounts of time in food preparation. Further to this, some treatment options (such as allergen immunotherapy) can have a significant positive impact on quality of life and may improve the course of disease but are expensive.

Treatment of allergic diseases is a rapidly evolving field and targeted therapies will continue to emerge. It is important that Australians are not disadvantaged in accessing these treatments if they are not Pharmaceutical Benefits Scheme (PBS) listed.

#### **Proposed solutions:**

- Medications and treatments:
  - Endorsement for expedient PBS listing of new TGA approved therapies with superior safety profiles.
- People with multiple allergic diseases:
  - People with more than one doctor diagnosed, severe allergic disease (severe allergic rhinitis, severe asthma, multiple food allergies, eczema) being able to access subsidies similar to the National Diabetes Services Scheme (NDSS).
- Funding for health economic analysis in collaboration with the National Allergy Strategy and the Centre for Food & Allergy Research (CFAR) would help to better understand the breadth of treatments and cost effectiveness.

#### **DISEASE SPECIFIC SOLUTIONS:**

- Allergic Rhinitis:
  - PBS listing of allergen immunotherapy prescribed by a clinical immunology/allergy specialist for the treatment of moderate to severe allergic rhinitis with or without asthma.
- Eczema:
  - PBS listing of Dupilumab as an effective and TGA approved therapy for people with severe eczema who otherwise need more harmful drugs that suppress the immune system.
  - A carers allowance for carers of children with severe eczema.

### **3. Better education and training is needed to prevent allergic reactions (including anaphylaxis) and improve diagnosis and management of all allergic conditions**

Quality education and training for health professionals about allergic diseases and anaphylaxis is often lacking and much needed. With the growing number of young adults with food allergies moving from paediatric to adult care, this will also become an issue for health professionals who manage adult patients.

#### **Proposed solutions**

- Federal government funding to implement recommendations from the National Allergy Strategy scoping report on the shared care model and for allergic diseases to be a more significant component of all health professional (including university and where relevant, post graduate) training. This includes collaboration with the Deans of major medical schools and with the Royal Australian College of General Practitioners (RACGP) and Royal Australasian College of Physicians (RACP) to help provide credible education.
- Funding for the sustainability of existing and ongoing development of resources by peak medical bodies (e.g. ASCIA) to ensure evidence-based, nationally standardised education is available to health professionals and the community.

### **4. The true incidence of anaphylaxis in Australia is not known and the rate of anaphylaxis presentation to emergency departments continues to rise. Deaths and near misses continue to occur due to mismanagement of anaphylaxis.**

Australia lacks a structured reporting system to capture data on the incidence of anaphylaxis, therefore the true incidence of anaphylaxis is unknown. An anaphylaxis notification scheme was recently established in Victoria but is only available in that state. Deaths from anaphylaxis have increased according to available data.

Across Australia, anaphylaxis continues to be mismanaged with many people treated sub-optimally – including not being given adrenaline (epinephrine) which is the first line treatment for anaphylaxis. Patients are discharged without a prescription for an adrenaline autoinjector (EpiPen<sup>®</sup>) or a referral to see a clinical immunology/allergy specialist for follow up care.

Existing anaphylaxis management guidelines, and there are several available across Australia, do not have indicators that assist local health services to monitor the quality of implementation. A national Clinical Care Standard does not exist but would help to address many of these issues.

#### **Proposed solutions:**

- Develop and implement an anaphylaxis register/notification scheme in every jurisdiction. The National Allergy Strategy has undertaken an initial scoping meeting for the development of an anaphylaxis register/notification scheme and this information can be provided on request. The anaphylaxis register/notification scheme should:
  - Capture fatalities and near misses as a result of anaphylaxis.
  - Enable the swift removal of foods with incorrect allergen labelling from the market place.
  - Allow prompt investigation of food premises with unsafe food allergen management practices.
  - Allow for pooled de-identified national data.
- Continued funding support for allergy prevention strategies:
  - Continued federal government support of the [National Allergy Strategy “Nip Allergies in the Bub” project](#) which aims to reduce the high rate of food allergy in Australia.
- Develop and implement a national anaphylaxis Clinical Care Standard by the Australian Commission on Safety and Quality in Health Care:
  - Clinical Care Standards require adherence and monitoring (as opposed to a guideline).
  - An anaphylaxis Clinical Care Standard has the potential to standardise clinical practice regarding anaphylaxis management in hospitals and across paramedic services Australia-wide.
- Changes to the PBS criterion for the dispensing of adrenaline autoinjectors:
  - Changing the PBS criterion to state that “All patients discharged from a hospital or an emergency department after anaphylaxis should be provided with an EpiPen prescription”.
  - A streamlined authority number for adrenaline autoinjector (EpiPen<sup>®</sup>) prescription.

#### **5. Management of allergen identification and minimisation is suboptimal in the food service sector, and in particular, those who provide meals for vulnerable institutionalised populations (e.g. hospitals, aged care settings).**

Allergic reactions to food purchased from the food service sector remains an issue for people with food allergy. Severe allergic reactions and tragically, fatal allergic reactions, continue to occur.

#### **Proposed solutions**

- Food service training:
  - A national standardised model for mandatory training for food service providers (similar to the responsible service of alcohol regulation) is suggested. The National Allergy Strategy has developed appropriate and freely available resources ([www.foodallergytraining.org.au](http://www.foodallergytraining.org.au)).
- Food Safety Supervisors:
  - A national requirement for all food businesses to have a Food Safety Supervisor with the requirement to undertake food allergen management training consistent with the National Allergy Strategy [Minimum Standards for Food Allergen Management in Food Service](#).
- Adoption of the [National Allergy Strategy food allergen management in hospitals resources](#) by all hospitals and other health institutions (e.g. aged care).
- Prompt and standardised investigations:
  - Prompt environmental health officer investigation of food service premises using standardised protocols in response to a reported food allergic reaction in food service. Where deaths have occurred, the investigation is carried out by the environmental health officer alongside police.

- Development and implementation of an anaphylaxis register/notification scheme to allow prompt investigation of food premises with unsafe food allergen management practices.

## 6. Precautionary allergen labels on foods continue to cause confusion and risks for individuals with food allergy.

Precautionary allergen labels (e.g. 'May contain ...' statements) are voluntary, unregulated and cause confusion for people with food allergy and health professionals. Most products contain a precautionary allergen label without any risk assessment being undertaken and therefore, the information is meaningless. Other products where there may be real risk, do not contain precautionary allergen labels and the individual is unaware of the risk. Further to this, if an individual with food allergy has an allergic reaction to a packaged food, it is critical that an investigation is undertaken, and the food product removed from the market place if the food is incorrectly labelled.

### Proposed solutions:

- Standardisation of precautionary allergen labels (i.e. 'May contain...' statements):
  - Mandate the requirement for food manufacturers to undertake an appropriate risk assessment (e.g. Voluntary Incidental Trace Allergen Labelling ([VITAL](#)) to determine whether a product requires a precautionary allergen label and standardisation of the wording used for precautionary allergen labels).
- Prompt and consistent investigations:
  - Prompt environmental health officer investigation and withdrawal of the food from the market place in response to a reported food allergic reaction to an incorrectly labelled packaged food. An anaphylaxis register/notification scheme to will facilitate this.

## 7. Drug allergy is misdiagnosed and poorly managed

Drug allergy is an important, complex and costly problem. Besides the risk of anaphylaxis, other adverse drug reactions (such as severe cutaneous adverse reactions or SCAR) may cause significant morbidity and mortality. Currently in Australia, there is no systematic way of collecting data about adverse drug reactions.

Up to 25% of patients presenting to hospital report a drug allergy (commonly antibiotics), which has a major impact on antimicrobial stewardship. Many studies have shown that only 10% of those claiming a drug allergy are truly allergic. The importance of a correct diagnosis of a person's drug allergy status is vital as this allows for the use of the most appropriate medications.

### Proposed solutions:

- A government funded drug allergy scoping project has been undertaken by the National Allergy Strategy. Implementation of the recommendations should be funded.
- Development and implementation of a national registry for SCAR is required (critical to preventing re-administering the drug).
- Clarifying a person's drug allergy status (commonly referred to as de-labelling):
  - An effective, nationally standardised drug allergy de-labelling guideline needs to be developed to ensure safe clarification of a person's drug allergy status (allergic/not allergic), thus reducing the use of second line antibiotics which are less effective, more expensive and have greater side effects.
  - Federal government support for a new MBS item number for drug allergen challenges to identify which patients have a true drug allergy.
- Clinical education:
  - Health professional training regarding accurate recording of adverse drug reactions, working toward the use of a national, standardised adverse drug reaction recording system.
- Improvements to the allergy section in My Health Record (MHR):
  - Allergy information in MHR must be accurate, current and easily discoverable (this is important for drug and food allergy).



- Standardised adverse drug reaction terminology should be implemented across Australia. This would assist health professionals and allow accurate data collection.
- Implementation of the allergy template for MHR developed by the National Allergy Strategy in partnership with the Australian Digital Health Agency.

## 8. Ongoing research into the causes, impact and treatment of allergic disease is minimally funded.

As there is no cure for food allergy, more research is needed into emerging management strategies. Food oral immunotherapy (OIT) is one such promising strategy. For most it is not a cure but may offer reduced anaphylaxis risk when accidental exposures to the allergenic food occur, thus potentially improving quality of life. The therapy itself poses the risk of serious side effects and expert supervision is critical. Individuals and families must be thoroughly informed about the risks and benefits of OIT and other emerging therapies in order to be involved in shared decision making and resources are lacking in this area. More research in the Australian context is needed. Implementation for food allergy OIT will require ongoing resource commitment and funding.

Better diagnostic tools for food and drug allergies are required as this may allow doctors to distinguish between food/drug tolerant and allergic patients without the need for skin testing and potentially harmful challenges; this would be a huge cost saver and make assessment of allergies a lot safer.

Qualitative research into the impact of allergic diseases on quality of life and childhood development is also required.

### Proposed solutions

- Food allergy OIT:
  - Funding for the development of a model looking at how best to deliver food allergy OIT in Australia and its implementation in all Australian states (to allow equitable access).
  - Fund the development and implementation of shared decision making tools to help patients/parents to make the right decision for them/their children about whether to undertake food allergy OIT.
- Diagnostic Tools
  - Recognise the need for better diagnostic tools in food and drug allergy and allocate/advocate for research funds for this area.
- Develop a process to assess and where deemed appropriate, deliver emerging therapies for allergic diseases.

### Our picture of future success...

- ✓ A reduction in the rate of food allergy in Australia.
- ✓ A reduction in the rate of deaths from anaphylaxis.
- ✓ Access to quality allergy/immunology care is equitable and timely. Existing collaborations between the National Allergy Strategy and partners are sustained and supported. Individuals and families are properly informed of the dangers of unvalidated diagnostics and therapies.
- ✓ A reduction in the financial and emotional/social costs of allergic disease.
- ✓ Prompt and affordable access to life changing allergy treatments in Australia.
- ✓ Access to food challenges in a safe facility is timely for everyone.
- ✓ Quality education in allergy for all health care professionals. Existing resources are sustained and supported.
- ✓ Uniform and high quality management of allergy and anaphylaxis across all health sectors including robust data about the incidence, causes and presentations of anaphylaxis via a register/notification scheme.
- ✓ The food service sector is well educated in food allergen management and is monitored appropriately to the highest standard.
- ✓ Food allergen labelling is logical, safe and useful.
- ✓ Drug allergies are properly identified, those who are not allergic are promptly “de-labelled” and documentation is robust.
- ✓ Increased support for research, particularly in relation to oral immunotherapy to keep Australia at the forefront of allergy diagnosis and management.

## PART 2 – Additional detail for each Term of Reference response

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### 1. The potential and known causes, prevalence, impacts and costs of anaphylaxis in Australia

#### Known causes of anaphylaxis

- Food (the most common include peanut, tree nut, egg, cow's milk, fish, shellfish, wheat, soy, sesame seeds, however, any food can cause anaphylaxis).
- Medications (common are antibiotics, anaesthetic drugs and contrast media used in radiology).
- Insect stings (bees, wasps, jack jumper ants, green ants).

Less common causes of anaphylaxis include:

- Physical (e.g. exercise, cold); biological agents (e.g. blood transfusions), latex, tick bites, idiopathic (cause unknown) and topical medications (e.g. chlorhexidine).

#### Proposed solutions

- Reduce the incidence of food allergy through food allergy prevention measures.
- Reduce the likelihood of exposure to allergenic foods through education.
- Investigate possible treatments for food allergy (for example oral immunotherapy) in supervised and regulated trials.
- Improve access to diagnosis and immunotherapy for insect allergy and improve consumer and health care education.

#### Potential and known causes of food allergy (and risk of anaphylaxis)

There is an incomplete understanding of why allergy, especially food allergy, has increased so rapidly in recent years, particularly in young children. It appears to be a complex interplay between a western lifestyle, environment and a genetic predisposition with no single trigger factor identified.

#### Proposed solutions

- Additional research in this area is required.
- Ongoing funding for and promotion of ASCIA infant feeding for food allergy prevention guidelines through the National Allergy Strategy [Nip allergies in the Bub website](#) and associated strategies.
- Improved access to accurate diagnosis thus reducing the risk of a mislabelled food allergy.

#### Incidence of anaphylaxis

In Australia there is no structured reporting system and/or resources to capture, collate and analyse data on the incidence of anaphylaxis, other than the anaphylaxis notification scheme recently established in Victoria as an outcome of a coronial recommendation. Therefore, the true incidence of anaphylaxis is unknown. Preliminary data from Victoria indicates that more than 1,000 cases were reported in the first 3 months of commencing the notification scheme and more than 600 of these were food allergy cases.

Many people diagnosed with food, insect or drug allergy are considered to be at risk of anaphylaxis, but current blood and skin prick tests only indicate likelihood of an allergic reaction, not severity of the reaction. The severity of an allergic reaction is unpredictable, however a previous anaphylaxis often means subsequent reactions will also progress to anaphylaxis.

Current data indicates:

- Hospital admissions for anaphylaxis have increased 5-fold in the last 20 years (1).
- Deaths from anaphylaxis in Australia have increased by 7% per year (1997-2013) (2).
- Food allergy induced anaphylaxis has doubled in the last 10 years (1).
- One in 10 infants now have confirmed food allergy (3) and 1 in 20 children aged 10-14 years of age have a food allergy (4).
- Approximately 3% of the Australian population is allergic to insect venoms (5).

## Proposed solutions

- Develop and implement an anaphylaxis register/notification scheme in every jurisdiction. The National Allergy Strategy has undertaken an initial scoping meeting for the development of an anaphylaxis register/notification scheme and this information can be provided on request.

The anaphylaxis register/notification scheme should:

- Capture fatalities and near misses as a result of anaphylaxis.
- Enable removal of foods with incorrect allergen labelling from the market place quickly.
- Allow prompt investigation of food premises with unsafe food allergen management practices.
- Allow for pooled de-identified national data.

## Impact of anaphylaxis

### *Deaths*

- The Australian Bureau of Statistics recorded 324 deaths from anaphylaxis between 1997 and 2013. Most deaths were attributed to an unspecified cause followed by medication, insect and food allergy. Almost all medication deaths occurred in older adults with multiple health conditions while young people under 30 made up the majority of the deaths from food (2). It is of great concern that most deaths were unspecified. Better education of health professionals and those doing coronial investigations could assist in determining causes soon after death.

### *Morbidity and quality of life*

- Anaphylaxis admissions are increasing (1) and while there may not be a fatal outcome, the anaphylaxis has a significant impact of the person experiencing the life threatening event, their family and potentially those caring for them at the time of the anaphylaxis (e.g. school or childcare staff), with some people requiring long term counselling after the anaphylaxis.
- Allergies to food, insects and drugs can be life-threatening and particularly for food and insect allergy, this can impact greatly on a person's quality of life (6,7).
- Food allergies and eczema disproportionately affect children and teenagers, impacting on their school performance, social life and general quality of life (8). Some allergies, particularly food and insect allergies, result in anaphylaxis, which more frequently occur outside the home except for the 0-4 year old age group, where most occur in the home (9).
- Individuals at risk of food-induced anaphylaxis and their carers have higher than average rates of anxiety (10-12). Some patients may require psychological assessment and support for post traumatic stress after experiencing anaphylaxis (13).
- Allergic diseases may affect career choices, including those pursuing careers within the Australian Defence Forces.

## Impact of allergic diseases

- The presentation of allergic diseases are becoming more severe and more complex. It is common for individuals to have disorders affecting several systems. For example, a child with peanut allergy often also has eczema and asthma.
- Many individuals have increased visits to their primary healthcare provider if their allergic diseases are not being managed effectively.
- Allergic diseases affect not only the individual but also their families in many ways (e.g. time off from work to attend medical appointments, cost of allergy medications many of which are not PBS subsidised, extra time caring for the child with allergic disease).
- Allergic rhinitis is a systemic allergic disease and is generally associated with other atopic disease (asthma, eczema). In allergic rhinitis, chronic congestion, sneezing and a decrease in restful sleep compromises daily activity including work and school performance.
- Delayed access to medical care and long waiting times for management of allergic diseases in all areas (rural, remote and metropolitan) is a major problem, due to the high number of diagnosed patients, newly diagnosed patients and low number of appropriately trained health care professionals (14).

- Other allergy related conditions such as food protein-induced enterocolitis syndrome (FPIES) and eosinophilic oesophagitis (EoE) are increasing (15,16) and these diseases have a significant impact on quality of life. Diagnosis of these conditions is difficult with parents/individuals seeking advice from many doctors before diagnosis and appropriate treatment.

### **Proposed solutions**

- Develop a national anaphylaxis Clinical Care Standard by the Australian Commission on Safety and Quality in Health Care.
- Improve access to timely and holistic health care (recommendations have been made in the Shared care model scoping report).
- Funding support for consumer and community resources (e.g. ASCIA e-training packages and referral to Allergy & Anaphylaxis Australia (national patient support organisation).
- Reduce exposure to allergenic foods in the food service setting by improving consumer, health professionals and food service provider education.
- Increase funding support for credible national patient support organisations (who have medical advisory boards such as Allergy & Anaphylaxis Australia), some of which offer a support line for individuals and families affected by allergic diseases.

### **Cost of anaphylaxis**

- A US study reported that childhood food allergy results in significant direct medical costs for the healthcare system and even larger costs for families with a child with food allergy (17).
- Although 5% of adults may be allergic to one or more drugs, up to 15% believe that they have drug allergy, and therefore are frequently unnecessarily denied treatment with an indicated drug (18).
- Up to 1 in 10 adults with suspected but unconfirmed drug allergy are often unnecessarily treated with more expensive drugs with greater adverse effects that may not be the optimal drug for their medical diagnosis. (8).

### **Cost of allergic diseases**

- Current public health policies overlook allergic diseases, causing great cost to society through hospital admissions and lost productivity, and to individuals by diminishing their quality of life.
- Allergic diseases have a significant economic impact, estimated at ~AU\$30 billion in 2005 (14).
- Non life-threatening allergic diseases can lead to absenteeism or lost productivity by those attending work when ill ('presenteeism'), poor academic performance and restricted social interaction due to the symptoms and the need to avoid certain allergens (19).
- Optimal eczema management requires at least twice daily liberal application of appropriate moisturisers all over the body. The moisturisers used are often expensive as they are designed specifically for managing eczema and more than one 500g tub a week is required to manage a teen or adult with eczema. In addition, steroid creams are used to manage eczema flares and at times antibiotics are also required if the eczema becomes infected. These are significant ongoing costs. If an individual/family cannot afford medications, this greatly impacts management of the chronic disease and has a greater impact on quality of life and health services.

### *Cost of medications*

- Medication costs related to the treatment of allergic rhinitis are estimated to be \$226.8 million in 2010 (20).
- Treatments such as allergen immunotherapy can change the course of allergic disease, but due to cost cannot be accessed by all who would benefit. Currently only bee and wasp immunotherapy is PBS listed.

### **Proposed solutions**

- Medications and treatments:
  - Consideration for expedient PBS listing of new TGA approved therapies with superior safety profiles.
- People with multiple allergic diseases:
  - People with more than one doctor diagnosed, severe allergic disease (severe allergic rhinitis, severe asthma, multiple food allergies, eczema) being able to access subsidies similar to the National Diabetes Services Scheme (NDSS).

- Funding for health economic analysis in collaboration with the National Allergy Strategy would help to better understand the breadth of treatments and cost effectiveness.

#### DISEASE SPECIFIC SOLUTIONS:

- Allergic Rhinitis:
  - PBS listing of allergen immunotherapy prescribed by a clinical immunology/allergy specialist for the treatment of moderate to severe allergic rhinitis with or without asthma.
- Eczema:
  - PBS listing of Dupilumab as an effective and TGA approved therapy for people with severe eczema who otherwise need more harmful drugs that suppress the immune system.
  - A carers allowance for carers of children with severe eczema.
- Funding for health economic analysis in collaboration with the National Allergy Strategy would help to better understand the breadth of treatments and cost effectiveness.

## 2. The adequacy of food and drug safety process and food and drug allergy management, auditing and compliance (including food allergen labelling by manufacturers and food service providers)

### Food allergen management in food service in Australia

#### *Allergic reactions*

- Reactions to food purchased from the food service sector remains an issue for people with food allergy. Despite awareness raising efforts by credible organisations, we continue to hear reports of severe allergic reactions and unfortunately, some fatal allergic reactions.
- Data from the Victorian Anaphylaxis Notification Scheme reports that from 1<sup>st</sup> November 2018 to 1<sup>st</sup> May 2019, 270 incidences of anaphylaxis (22% of all anaphylaxis events reported) reported in emergency departments, were due to unpackaged food from a food premises. While we do not have a comparable system in other states/territories to collect similar data, anecdotally, we know that reactions to foods consumed within the food service sector are occurring in other jurisdictions through reactions being reported to Allergy & Anaphylaxis Australia.
- Most allergic reactions in food service when a consumer discloses their food allergy, occur because the allergen is a component of the meal, not because of cross contamination of utensils for example. Poor communication between front of house and back of house staff is commonplace.

#### *Vulnerable populations*

- It is important to note that some populations are more vulnerable than others.
- People with food allergy where English is the second language are at increased risk.
- People with food allergy are more vulnerable and at greater risk of a more severe anaphylaxis when they are unwell, particularly if their asthma is not well managed.
- People with food allergy who are suffering from mental illness such as dementia are also at increased risk because they cannot effectively disclose their allergy/check their food.
- Food service providers in institutions, where the population may be at increased risk, have an increased level of responsibility in providing an appropriate food service as the patient with food allergy may not be able to undertake the usual communications (e.g. medications may affect their mental state, dementia etc) to check the food is free of the food they are allergic to.
- Data from the Victorian Anaphylaxis Notification Scheme (1<sup>st</sup> November 2018 – 1<sup>st</sup> May 2019) reports that the majority of anaphylaxis events to unpackaged food from a food premises, is in the 10-19 year age group (71 anaphylaxis events) and the 20-29 year age group (64 anaphylaxis events). Teens and young adults are at increased risk of fatal anaphylaxis and therefore, preventing anaphylaxis in this age group is important. While several factors contribute to their increased risk, all opportunities to reduce the risk of exposure to known allergens, including increased education of both consumers and food service providers, must be considered.

### *Training*

- Currently, the food allergen content in accredited training courses for those working in food service is variable in quality and quantity.
- The National Allergy Strategy released the All about Allergens online training in July 2017 and this course aims to provide free, standardised training accessible to all working in food service. Until the All about Allergens course was released, access to food allergen management training was limited for the following reasons:
  - The course did not contain food allergen management information or only contained limited information about food allergen management;
  - The cost of undertaking the course was prohibitive; or
  - The time required to undertake the course was prohibitive.
- The National Allergy Strategy consulted with and considered challenges faced by food service businesses when developing the All About Allergens training. The high turnover of young staff was top of mind when the National Allergy Strategy developed training that was fast, easy and free.

### *Current strategies*

*Australia's Foodborne Illness Reduction Strategy 2018-21+* which aims to improve food safety management in the horticulture and food service sectors as priority focus areas, does not address food allergen management as food allergy was not considered a hazard. However, food borne illness is noted as a priority area and one could argue that a person experiencing an allergic reaction (potentially a severe allergic reaction which could result in a fatality) due to being served a food they have declared they are allergic to, is a food borne illness.

### *Food safety supervisors – current status in Australia*

Currently in Australia only NSW, ACT, QLD and VIC require businesses to have a food safety supervisor. In the jurisdictions where a food safety supervisor is required, there are differences with regards to:

- Which businesses are required to have a food safety supervisor and the reasoning behind why they need to have a food safety supervisor;
- The training requirements for food safety supervisors;
- Whether a period of currency applies to the training required; and
- Regulation of training provided to food safety supervisors.

Currently, NSW is the only jurisdiction that regulates the training for food safety supervisors and NSW have included food allergen management in this training. Currently, only two jurisdictions stipulate a period of currency for food safety supervisor training.

### **Proposed solutions**

- Food service training:
  - A national standardised model for mandatory training for food service providers (similar to the responsible service of alcohol regulation) is suggested. The National Allergy Strategy has developed appropriate and freely available resources ([www.foodallergytraining.org.au](http://www.foodallergytraining.org.au)).
- Food Safety Supervisors:
  - A national requirement for all food businesses to have a Food Safety Supervisor with the requirement to undertake food allergen management training consistent with the National Allergy Strategy [Minimum Standards for Food Allergen Management in Food Service](#).
- Adoption of the [National Allergy Strategy food allergen management in hospitals resources](#) by all hospitals and other health institutions (e.g. aged care).
- Prompt and standardised investigations:
  - Prompt environmental health officer investigation of food service premises using standardised protocols in response to a reported food allergic reaction in food service and where deaths have occurred, the investigation is carried out by the environmental health officer alongside police.
- Development and implementation of an anaphylaxis register/notification scheme to allow prompt investigation of food premises with unsafe food allergen management practices.
- Ongoing education of teens and young adults through the [National Allergy Strategy 250K youth project](#) to educate young people about eating out with food allergy.

- Inclusion of an accredited food allergen management training course that meets the National Allergy Strategy [Minimum standards for food allergen management training](#), in all hospitality training courses.
- A national standardised approach to raise awareness that food safety management includes food allergen management. Not addressing food allergen management in *Australia's Foodborne Illness Reduction Strategy* gives the message that food allergens and food allergy are not important and certainly not a priority.
- Mandatory requirement of Food safety supervisors in all food businesses in all jurisdictions.
- Mandatory requirement for Food safety supervisor training to be undertaken at least every two years and to include the National Allergy Strategy [All about Allergens](#) online training allowing for standardisation of training across Australia.
- Mandatory requirement for food safety supervisors to demonstrate that effective processes are in place to manage food allergens in their food business. This should be undertaken by the inclusion of effective questions relating to food allergen management in audit and inspection tools used by Environmental Health Officers and other authorised officers.

### **Food allergy and packaged food**

In Australia, legislation currently mandates the inclusion of common food allergens (peanut, tree nuts, egg, milk, fish, crustacea, soy, sesame, lupin and gluten) on the label of packaged foods where the food is an intended ingredient. Food Standards Australia New Zealand (FSANZ) is undertaking work to improve plain English allergen labelling to standardise the way the common food allergens are included on food labels when added as an intended ingredient and this work will help consumers and those preparing food for consumers with food allergy, to read and understand labels.

However, a major issue in Australia and internationally, is precautionary allergen labels (e.g. 'May contain ...' statements), which are voluntary and unregulated and cause confusion for individuals with food allergy as well as health professionals as they are unsure what advice to give. Some products contain a precautionary allergen label due to a thorough risk assessment with the outcome identifying clear risk for the allergic consumer. However, other products contain a precautionary allergen label without any risk assessment being undertaken and therefore, the information is meaningless. Other products where there may be real risk, do not contain precautionary allergen labels and the consumer is unaware of the risk. Therefore, the current information provided to allergic consumers through precautionary allergen labels is relatively meaningless unless the individual rings the manufacturer to find out if they have undertaken a risk assessment and what that risk assessment entailed.

### *Imported foods*

While there are processes in place to check imported foods are appropriately labelled, they are currently not meeting the required need and incorrectly labelled products are being imported and allowed in the Australian marketplace.

To protect consumers with food allergy, there needs to be a higher priority for checking compliance and accuracy of labelling upon importation, particularly when suppliers may change (e.g. supermarket "home brand" products) or those compiled from local and imported ingredients. Increased education of food importers and distributors is required to ensure all allergens are listed and they are compliant with Australian food labelling laws. This includes the development and implementation of a process to ensure accurate food labelling stickers (including accurate translations) are placed on the product and ensuring corrective over-stickers are applied where required.

### **Proposed solutions**

- Mandate the requirement for food manufacturers to undertake an appropriate risk assessment (e.g. [VITAL](#)) to determine whether a product requires a precautionary allergen label.
- Standardisation of precautionary allergen labels (e.g. [VITAL](#)).
- Provision of standardised education for food importers regarding Australian food label requirements for food allergens.
- Increased resourcing for imported foods to be checked for correct allergy labelling.
- Implementation of a process to ensure accurate food label stickers (including appropriate translations) are placed on the product.

### **Australian Commission on Safety and Quality in Health Care Medication chart**

The medication chart developed by the Australian Commission on Safety and Quality in Health Care is currently being underutilised with regards to documentation of a patient's allergies. The reason for this is that there is currently not enough space to adequately document all of the patient's allergies and therefore some are being missed or documented elsewhere. If allergies are documented elsewhere, they are more likely to be missed leading to poor outcomes.

#### **Proposed solutions**

- Modification of the Australian Commission on Safety and Quality in Health Care standard medication chart to include more space to document allergies.

### **3. The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis**

#### **Anaphylaxis Clinical Care Standard**

Despite having nationally standardised anaphylaxis management guidelines, deaths and near misses continue to occur due to suboptimal emergency treatment of anaphylaxis. Guidelines are less effective than Clinical Care Standards as Clinical Care Standards require adherence, monitoring and audits.

The evidence supporting action to improve anaphylaxis management is as follows:

- Australian studies have highlighted continuing issues in variation of acute management of anaphylaxis. One study reviewed anaphylaxis management in eight Australian emergency departments and found that:
  - 27% of reactions consistent with anaphylaxis were NOT given adrenaline (epinephrine). Adrenaline is the first line treatment for anaphylaxis (21).
  - For 5.7% of reactions, the patient was given subcutaneous adrenaline which is the incorrect route of administration (adrenaline should be administered via intramuscular injection resulting in quicker reversal of symptoms) (21).
- Further to this, variation exists with regards to follow-up care for anaphylaxis in Australian emergency departments:
  - Less than 50% of patients that experience anaphylaxis are provided with a prescription of self-injectable adrenaline (e.g. EpiPen®) when discharged (22).
  - Only 33% of patients that experience anaphylaxis are referred to a clinical immunology/allergy specialist (22).
- Of those who have died from anaphylaxis in Australia, the majority were not under the care of a clinical immunology/allergy specialist which has become evident through coronial inquiries and contact with other families.

Further to this, the [coronial findings and recommendations for Kylie Lynch](#) indicated that within one state (Western Australia), four different anaphylaxis acute management protocols existed at the time of her death. The [coronial inquest for Louis Tate](#) also raised concerns regarding appropriate management of anaphylaxis.

Existing anaphylaxis management guidelines (and there are several available across Australia), do not include quality statements that succinctly describe the key aspects of care that a patient experiencing anaphylaxis should be offered. Even if there were quality statements included in the guideline, there are no indicators that accompany the quality statements to assist local health services to monitor how well they implement the care described.

#### **Proposed recommendations**

- Development and implementation of an anaphylaxis Clinical Care Standard by the Australian Commission on Safety and Quality in Health Care.



- The development of an anaphylaxis Clinical Care Standard would address the ongoing challenges with variation in the anaphylaxis management in hospitals often to the detriment of the patient, and would also help to standardise acute management of anaphylaxis across paramedic services nationally.
- Dissemination of, and recommendations to undertake the ASCIA anaphylaxis e-training for health professionals, would provide standardised, evidence-based education.

### **Drug allergy clinical education requirements**

A person's safety is paramount and appropriate management of people with drug allergy requires health professionals to have a good understanding of adverse drug reactions including drug allergy and the consequences of administering a drug to a patient with drug allergy. Further to this, a person's clinical information is only useful if the information is accurate and most current. Incorrect clinical records can result in harm to the person if they are given a medication they are allergic to, or if they are unnecessarily avoiding a medication. Over diagnosis of drug allergy, particularly penicillin allergy, can have an ongoing impact on the person's health, as avoiding first line antibiotics results in longer hospital stays, more hospital re-admissions and contributes to antimicrobial resistance.

The National Allergy Strategy has undertaken a scoping project with regards to drug allergy clinical education requirements, funded by the Australian Government Department of Health. This report may help inform this parliamentary inquiry and should the Committee overseeing this inquiry wish to view the information collected including our draft recommendations, the information will be provided by the National Allergy Strategy Manager with permission from the Department of Health.

### **Proposed solutions**

- Implementation of the recommendations of the National Allergy Strategy drug allergy scoping project.

### **Health professional training**

Many health professionals undertake minimal training in allergy, if any, during their health degree. Various health professional training courses are available either face to face or as online learning. The quality of these courses is variable, and some may be influenced by funding providers.

### **Proposed solutions**

- Support for sustainability of existing resources developed by peak medical bodies (e.g. ASCIA) to ensure evidence-based, nationally standardised education is available, particularly where the courses are currently available free of charge.
- Fund the recommendations of the National Allergy Strategy shared care model scoping report (see below).
  - These recommendations include collaboration with the Deans of major medical schools and with the Royal Australian College of General Practitioners (RACGP) to help provide credible education. It will allow allergic diseases to be a more significant component of all health professional university training.

## **4. Access to and cost of services, including diagnosis, testing, management, treatment and support**

### **Shared care model for allergy**

It is essential that people with allergic diseases are able to access appropriate care by appropriately trained and knowledgeable health professionals. A shared care model is required for all allergic diseases, not just food allergy and anaphylaxis, as allergic rhinitis (hay fever) and eczema also have a significant impact on quality of life.

Developing a shared care model for allergy does not simply mean upskilling general practitioners or paediatricians to manage more patients with allergic diseases. A shared care model focusses on ensuring that all health professionals understand the needs of the patient with allergy and their role in managing the patient's allergy.

Existing issues include:

- Access to appropriate care is often delayed with long waiting times to see medical specialists such as clinical immunology/allergy specialists, dermatologists, paediatric gastroenterologists and allied health professionals (e.g. allergy dietitians, psychologists).
- Long waiting times, particularly in public hospitals, for clinical immunology/allergy specialist appointments has resulted in people seeking advice from alternative/unorthodox health practitioners.
- Absence of appropriate care carries a significant risk of serious adverse events in a relatively well population and increases healthcare encounters and associated costs.
- People are not being referred by primary healthcare providers for assessment by appropriate medical specialists.
- Access to care in rural and remote areas is inequitable, particularly as most medical specialists are based in cities.
- Access to prompt specialist follow up after anaphylaxis is currently sub-optimal.
- Other conditions such as food protein induced enterocolitis syndrome (FPIES) and eosinophilic esophagitis (EoE) are often difficult to diagnose and may require management by a number of subspecialties and a team approach.

The National Allergy Strategy is currently scoping a shared care model for allergy with the report due for submission to the Australian Government Department of Health in December 2019. This report cannot be shared in a public submission but will help inform this parliamentary inquiry. Should the Committee overseeing the inquiry request the report, permission will be sought from the Australian Government Department of Health to provide it.

#### **Proposed solutions**

- Fund the recommendations of the National Allergy Strategy shared care model scoping report.
- Fund the development and implementation of shared decision making tools.

#### **Patient support organisations**

Access to credible national patient support organisations with a medical advisory board is important in helping people to manage their allergies. At the time of diagnosis, patients have many questions and often don't take in all the information provided by the doctor as it can be overwhelming, particularly if they or their child has experienced a severe allergic reaction (anaphylaxis). In addition, it is not possible for clinical immunology/allergy specialists to cover all aspects of allergy management in an appointment.

Patient support organisations are able to provide practical advice and resources about how to manage allergic diseases in daily life. There are many times in a person's life when they may need support to manage their allergy and it is often around the time of diagnosis and when experiencing firsts (e.g. travelling with food allergy, their child starting childcare or school) and when experiencing allergic reactions including anaphylaxis.

#### **Proposed solutions**

- Raise awareness amongst health professionals regarding the value of credible patient support organisations in helping patients to manage their allergic disease.
- Credible patient support organisations who are supported by a medical advisory board should be sufficiently funded to provide this valuable service.

#### **Cost of treatments**

##### *Costs for patients*

People often have multiple allergic diseases and families often have multiple family members with allergic diseases resulting in a significant cost for allergy medications. Many medications that can significantly improve quality of life for people with allergic diseases are expensive and currently not subsidised, therefore not accessible for many.

### *Costs for patients and clinicians*

Providing access to food and drug challenges in private practice by clinical immunology/allergy specialists is increasing due to long waiting times for these services in the public system. Food and drug challenges take several hours with at least two hours of monitoring of the person after the last dose of the food or drug to monitor for anaphylaxis. Those that have anaphylaxis as a result of the food challenge must stay in hospital for at least four hours post the last dose of adrenaline received. Challenges to food involve gradually increased, meticulously measured doses of allergen given at 20 minute intervals with close observation and readiness for rapid emergency treatment.

Currently, there is no MBS item number that allows clinical immunology/allergy specialists to appropriately bill for this service, and providing this service incurs significant financial cost to the clinician as well as professional stress in monitoring the person and managing an anaphylaxis should it occur. Many health insurers do not recognise the procedure without an MBS item number so despite paying for private health insurance, people may have to pay up front for beds in a private hospital as their insurance will not pay. Private hospitals are thus reluctant to take on the burden of offering food challenges. Often, the person (usually a child) will require multiple challenges and the family can incur significant costs or be forced to wait months to years for a bed in the public setting.

In frustration, some parents are giving the potentially allergenic food to their child outside the clinician's medical rooms and if an anaphylaxis occurs, the clinician needs to manage the anaphylaxis. Parents are also giving children foods outside emergency departments because of the fear of allergic reactions. This is clearly unsafe and not ideal.

### **Proposed solutions**

- Medications and treatments:
  - Consideration for expedient PBS listing of new TGA approved therapies with superior safety profiles.
- People with multiple allergic diseases:
  - People with more than one doctor diagnosed, severe allergic disease (severe allergic rhinitis, severe asthma, multiple food allergies) being able to access subsidies similar to the National Diabetes Services Scheme (NDSS).
- Funding for health economic analysis in collaboration with the National Allergy Strategy would help to better understand the breadth of treatments and cost effectiveness.

### **DISEASE SPECIFIC SOLUTIONS:**

- Allergic Rhinitis:
  - PBS listing of allergen immunotherapy prescribed by a clinical immunology/allergy specialist for the treatment of moderate to severe allergic rhinitis with or without asthma.
- Eczema:
  - PBS listing of Dupilumab as an effective and TGA approved therapy for people with severe eczema who otherwise need more harmful drugs that suppress the immune system.
  - A carers allowance for carers of children with severe eczema.
- Food/drug allergy
  - Provision of an MBS item number for food and drug challenges undertaken by clinical immunology/allergy specialists in private practice.

## **5. Developments in research into allergy and anaphylaxis including prevention, causes, treatment and emerging treatments (such as oral immunotherapy)**

### **Allergy prevention**

Optimal management of allergic diseases can help to reduce the likelihood of further development of associated allergic diseases and complications. (e.g. optimal management of allergic rhinitis may reduce the risk of developing asthma or obstructive sleep apnoea (23)).

Studies show that introducing peanut between 4-11 months of age can reduce peanut allergy in high risk infants by 80% (24). Peanut allergy is most commonly life-long with the majority of peanut allergic individuals needing to carry an adrenaline autoinjector (e.g. EpiPen®) for life. Preventing the development of peanut allergy will not only greatly improve the quality of life for individuals and their families, but it can assist in reducing the cost to government, individuals with allergy and the community in the following ways:

- Reduced presentations to hospital and hospitalisations for severe reactions (hospital admissions for food allergy induced anaphylaxis have increased 4-fold in the last 14 years (1)).
- Reduced ambulance call outs and emergency department admissions.
- Reduced GP visits (Medicare).
- Reduced public allergy clinic visits.
- Reduced PBS subsidised adrenaline autoinjector (EpiPen®) prescriptions (most individuals with peanut allergy will require an EpiPen® for life).
- Reduced need for government subsidised psychological care due to the stress food allergy management and potentially life-threatening allergic reactions, places on both the parent and child.
- Reduced costs for individuals and families for doctor visits (including specialists) and medications.

#### **Proposed solutions**

- Continued funding support for allergy prevention strategies:
  - Continued federal government support of the [National Allergy Strategy “Nip Allergies in the Bub” project](#) which aims to reduce the high rate of food allergy in Australia.
- The National Allergy Strategy Nip Allergies in the Bub project collects data from parents regarding the introduction of common food allergens in the first year of life and parent-reported reactions to foods introduced. This allows the monitoring of parental behaviours regarding compliance with the ASCIA guidelines as well as monitoring allergic reactions.

#### **Improving access to effective treatments**

Current effective treatments and emerging treatments can significantly improve the quality of life of individuals with allergic diseases and their carers. Food allergy OIT is a promising management strategy for food allergy. For most it is not a cure but may offer reduced anaphylaxis risk when accidental exposures to the allergenic food occur, thus potentially improving quality of life. The therapy itself poses the risk of serious side effects including an increased risk of anaphylaxis which may be higher than conventional management (food avoidance). Individuals and families must be thoroughly informed about the risks and benefits of such therapies in order to be involved in shared decision making and resources are lacking in this area. More research in the Australian context is needed. Implementation for food allergy OIT will require ongoing resource commitment and funding.

#### **Proposed solutions**

- Food allergy OIT:
  - Develop a model of how best to deliver food allergy OIT in Australia and fund implementation.
  - Fund the development and implementation of shared decision making tools to help patients/parents to make the right decision for them/their children about whether to undertake food allergy OIT.
  - Collect information regarding the effectiveness and safety of the treatment, including quality of life measures by the participants.
- Develop a process to assess and where deemed appropriate, deliver emerging therapies for allergic diseases.

#### **Research into psychosocial aspects of food allergy**

It is unclear why some people can accept their food allergy and manage their food allergy well, while others are overly anxious and are sometimes unrealistic in their demands on society to increase their safety. In order to make anxiety more manageable and preclude treatment decisions based on fear rather than fact, research in this area is needed.

#### **Proposed solutions**

- Undertake research to understand what services and resources would help to educate and support allergic individuals (and/or their parents).

### **Research into better diagnostic tools for food and drug allergy**

Currently diagnostic tools for food and drug allergy are limited. Research around the world continues to help better identify people who are truly allergic, who is at the greatest risk of anaphylaxis and even who may benefit most from particular therapies.

#### **Proposed solutions**

- More research funding into developing diagnostic tools for food and drug allergy

## **6. Unscientific diagnosis and treatments being recommended and used by some consumers**

### **Management of allergic diseases by alternative health practitioners**

Individuals often seek diagnosis and treatment from alternative health practitioners, particularly when there is a delay in access to care and/or when treatment options are limited. Alternative health practitioners often use [unvalidated testing methods](#) and treatment options which can be expensive to the allergic consumer. In addition, advice can be unsafe and put the individual at increased risk through over-restricted elimination diets (26). The [Friends of Science in Medicine](#) have written extensively on this.

#### **Proposed solutions**

- Education of consumers about the risks associated with unscientific diagnosis and treatments for allergic diseases.
- Improve timely access to allergy services for patients.
- Early referral to credible national patient support organisations to assist with management in everyday life.

## **7. The impact of unnecessary drug avoidance due to unconfirmed drug allergies and its management, such drug allergy ‘de-labelling’**

### **Drug allergy management**

To ensure the safety of the person and effective use of medications, there are two key issues that need to be addressed with regards to drug allergy:

- People with confirmed severe drug allergies and adverse drug reactions must never receive the drug.
- People are often documented (‘labelled’) as having a drug allergy when they are not allergic to the drug.

#### *Cost savings can be achieved*

Many people are considered to be allergic to one or more drugs, most commonly antibiotics, usually because they have had adverse symptoms or a reaction whilst taking the drug. In some cases, this is valid, and the drug should be avoided. However, in many cases the person is not truly allergic because the symptoms were not actually caused by the drug, but rather the illness they had at the time (e.g. virus). Furthermore, the perception of allergy might be based on childhood reactions that are no longer relevant, or on entirely spurious information (e.g. the wrong drug, or a family member with allergy).

Confirmation or clarification of drug allergy reduces costs by allowing basic, safe and cheaper drugs (particularly antibiotics) to be used in those who are not allergic, which might otherwise be avoided unnecessarily. It prevents complications, results in shorter hospital stays, reduces readmissions and reduces the rate of bacterial antimicrobial resistance (in the case of antibiotics) in the community.

The National Allergy Strategy has undertaken a drug allergy scoping project and this report will help inform this parliamentary inquiry. The report recommendations cannot be included in a public submission, however the Committee overseeing the inquiry can request a copy of this report and permission will be sought from the Australian Government Department of Health.

#### **Proposed solutions**

- A government funded drug allergy scoping project has been undertaken by the National Allergy Strategy. Implementation of the report recommendations should be funded.
- Development and implementation of a national registry for SCAR is required (critical to preventing re-administering the drug).
- Clarifying a person's drug allergy status (commonly referred to as de-labelling):
  - The importance of a correct diagnosis of a person's drug allergy status is vital as this allows for the use of the most appropriate medications.
  - An effective, nationally standardised drug allergy de-labelling guideline needs to be developed to ensure safe clarification of a person's drug allergy status (allergic/not allergic), thus reducing the use of second line antibiotics which are less effective, have greater adverse effects and are more expensive.
  - Federal government support for a new MBS item number for drug allergen challenges to identify which patients have a true drug allergy.
- Clinical education:
  - Health professional training regarding accurate recording of adverse drug reactions, working toward the use of a universal (national), standardised adverse drug reaction recording system.
- Improvement of drug allergy section in MHR:
  - Allergy information in MHR must be accurate, current and easily discoverable (this is important for drug and food allergy).
  - Standardised adverse drug reaction terminology should be implemented across Australia. This would assist health professionals and allow accurate data collection.
  - Implementation of the allergy template for MHR developed by the National Allergy Strategy in partnership with the Australian Digital Health Agency.

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