Committee Secretariat
Standing Committee on Health, Aged Care and Sports
PO Box 6021
Parliament House
Canberra ACT 2600

7 November 2019

Dear Standing Committee,

Allergy & Anaphylaxis Australia (**A&AA**) welcomes the opportunity to comment on the terms of reference of the House of Representatives parliamentary inquiry into allergies and anaphylaxis in Australia (**Inquiry**). A&AA also refers to the National Allergy Strategy (**NAS**) Submission, which is a joint submission on behalf of the Australasian Society of Clinical Immunology and Allergy (**ASCIA**) and A&AA.

We thank the Australian government for recognising the importance of allergic disease and progressing the Inquiry.

A&AA believes the following should be prioritised as part of the Inquiry:

- timely access to quality, holistic care for people affected by allergic disease;
- improved education of people with allergic disease and all involved in their care;
- improved prevention and consistent treatment of anaphylaxis in all healthcare settings;
- reduced cost burden for people affected by allergic disease without compromising the quality of services or treatment; and
- improved safety for consumers affected by allergic disease, including in relation to packaged foods and in food service settings.

A&AA is available to assist the Standing Committee as required throughout the Inquiry.

Yours sincerely,

[redacted]

Maria Said RN
CEO, Allergy & Anaphylaxis Australia
[redacted]

Allergy & Anaphylaxis Australia

Your trusted charity for allergy support

House of Representatives Standing Committee on Health, Aged Care and Sport Inquiry into allergies and anaphylaxis in Australia

A submission from Allergy & Anaphylaxis Australia

[redacted]

Contents

1. Executive summary

Allergic disease has increased in prevalence and complexity over the last 20 years. Australia is reported to have one of the highest rates of allergic disease globally. For the most part, allergic disease is chronic and has no cure. Many Australians have more than one allergic disease state and many families have several family members with allergic disease. Moderate to severe allergic disease, no matter which disease state, is a burden on the individual, the family and the healthcare system.

Access to appropriate care is challenging as Australia has a limited number of allergists and clinical immunologists and there is a need to educate and upskill other health professionals in optimal management of allergic disease. The lack of access to timely allergist consults and the lack of health professional education result in many Australians with allergic disease not being accurately diagnosed and treated according to current best practice. This paradigm also leads to individuals and parents desperately seeking answers from alternative practitioners who often perform testing and treatments that have little or no scientific basis.

As access to allergists and clinical immunologists is often difficult, individuals with non-life threatening allergic disease are often bumped to the bottom of waiting lists. This means that potential successful treatments such as immunotherapy for environmental allergies are not discussed, as general practitioners are aware of long waiting lists and specialists must commence immunotherapy. The impact that the unavailability of treatments to individuals severely affected by significant disease has on their quality of life is seriously concerning. People with severe disease, such as those with debilitating atopic dermatitis, often lose hope that their condition, which affects every aspect of their life, will ever improve. Many feel isolated and knowing that a treatment that can significantly improve their quality of life is unreachable, further affects their physical and mental health and general wellbeing.

Australia needs allergic disease to be understood as a chronic disease state that affects the lives of more than four million individuals. The burden of disease on individuals and the healthcare system is increased even further when people cannot access the optimal healthcare and ongoing treatments they need. Many disease states require multiple medications and daily treatments for optimal management, the financial cost of which is significant. The majority of medications for allergic disease are not PBS-listed and immunotherapy for environmental allergens such as house dust mite and pollens, which can cause severe allergic asthma, allergic rhinitis and eczema, are not within reach for many people, as they are too expensive.

There is a need for a coordinated response to the rise in allergic disease. While ASCIA and A&AA (through the NAS) and other major key stakeholders are doing what they can with limited resources, more needs to be done to prevent, diagnose, treat and manage allergic disease in everyday life. The current ‘bandaid approach’ to allergic disease and its management is increasing the burden on all, including the healthcare system. Accurate diagnosis of those with antibiotic allergy, for example, would improve health outcomes for individuals, reduce government costs (by avoiding the use of more expensive and potentially sub-optimal antibiotics) and potentially reduce the risk of antimicrobial resistance.

Hospital admissions due to food allergy have increased four-fold over the past ten years. The effect on quality of life is significant. Timely diagnosis and access to evidence-based information and support is critical. There is an urgent need for improved food manufacturing practices and food allergen labelling of both Australian-made and imported food products. Targeted education of all food service staff is paramount as is education of compliance officers across Australia. While there has been much progress in the area of food safety, there are initiatives that need to be progressed to improve safety and decrease the number of life-threatening allergic reactions and fatalities.

There is much that we can learn from a register that captures anaphylaxis events and fatalities. Deaths from anaphylaxis or suspected anaphylaxis need to be reported to the state coroner. The small number of coronial investigations and inquests have assisted A&AA, ASCIA (and therefore the NAS) in better supporting, informing, educating and guiding individuals, families, schools, camp facilities, food service establishments, sporting clubs and institutions, such as hospitals, in improving care and safety.

Medical management of anaphylaxis varies across the country despite ASCIA's evidence-based recommendations for emergency treatment. Development of a clinical care standard for anaphylaxis is urgently needed as we continue to receive reports of sub-optimal emergency care that affects the health and ongoing care of individuals at risk of anaphylaxis. Delayed use of adrenaline in the health care setting, and use of less invasive medications that are not meant for the initial treatment of anaphylaxis contributes to the delayed administration of adrenaline by individuals in the community setting. This practice increases the risk of fatal outcomes.

Further research to assist with prevention, diagnosis, understanding of allergic disease pathways and human response, current and emerging treatments, and psychosocial aspects of allergic disease manifestations needs to continue so that those with allergic disease can work towards an improved quality of life.

Continued education of Australians with and without allergic disease, including health professionals, the food industry, schools, and workplaces can help improve general health and wellbeing of people with allergic disease. As many without allergic disease do not understand the challenges, people with allergic disease who often need to be better informed about management are often poorly understood and supported. Access to timely and quality care, accurate information, treatment plans, affordable medications and treatments, and ongoing support means the individual with allergic disease (and their family) has the tools they need to live a close-to-normal life.

2. List of recommendations

Term of reference 1—The potential and known causes, prevalence, impacts and costs of anaphylaxis in Australia

- Improve community education by increasing the sharing of freely available educational information through ASCIA, A&AA and the NAS.
- Refer at-risk individuals to an allergist and an evidence-based national patient support organisation, such as A&AA.
- Establish state-based registers to allow systematic reporting of anaphylaxis events that can then be de-identified and compiled to form a national register.
- Require all deaths from anaphylaxis or suspected anaphylaxis to be reported to the coroner and increase the number of coronial inquests into deaths from anaphylaxis, particularly where the inquest is likely to facilitate an understanding of allergy management and improved safety.

Term of reference 2—The adequacy of food and drug safety processes and food and drug allergy management, auditing and compliance (including food allergen labelling by manufacturers and food service providers)

- Mandate precautionary allergen labelling alongside the Voluntary Incidental Trace Allergen Labelling (**VITAL**) process, including the VITAL Standard and the VITAL symbol on packaging, so that people can have clarity and confidence in the allergen information shared on packaging.
- Require food manufacturers to communicate changes in allergen ingredients on the front of a pack and also alert national support organisations, such as A&AA, of the change. If the old and new products are on the shelf at the same time, this also needs to be communicated.
- Encourage food manufacturers to consider food allergy when creating families of products, different size packs of the same products, and different versions of products that have different allergen content by communicating this on packaging, differentiating packs, and sending alerts to A&AA to share with consumers managing food allergy.
- Translate the Food Standards Code (**FSC**) and other relevant guides into the most common languages so business-owners from culturally and linguistically diverse backgrounds or those with low English literacy have access to legislative requirements and best practice guidelines around labelling of packaged food made in and imported into Australia. Translations would also assist the food service industry.
- Improve community education on eating away from home with food allergy and risk reduction for online ordering for individuals and their carers.
- Require anyone working in food service to successfully complete the basic free National Allergy Strategy 'All About Allergens' e-training (similar to the Responsible Service of Alcohol certificate for those working in licenced premises).
- Require every food service facility across Australia to have a Food Safety Supervisor trained in food allergy.
- Translate food legislation and guides into languages other than English to assist food service proprietors and staff.

- Improve education and audit tools for environmental health officers by including information on food allergy management in food service.

Term of reference 3—The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis

- Increase the education component in health professional training on allergic disease.
- Increase the number of training positions for allergy specialists.
- Increase awareness among health professionals of current freely available resources, including e-training.
- Fund ASCIA to provide free e-training courses, including Continued Professional Development (**CPD**) points for health professional training courses.
- Improve support for general practitioners (**GPs**) to increase their allergy awareness and skills (consider a mentor system with an allergist/allergy clinic).
- Increase use of telehealth to connect rural and remote patients to allergists.
- Develop and roll out a national clinical care standard for anaphylaxis.
- Adopt and implement national minimum standards for food allergy and anaphylaxis management (developed by the National Allergy Strategy in consultation with key stakeholders) in schools and early childhood services.
- ALL schools and early childhood services provide Adrenaline autoinjectors for general use in first aid kits.

Term of reference 4—Access to and cost of services, including diagnosis, testing, management, treatment and support

- Increase subsidies for medications used to prevent and treat allergic disease.
- Subsidise medication for people with more than one allergic condition to reduce the financial stress of allergic disease.
- Subsidise existing subsidised medications used to treat one allergic condition for use with other allergic conditions where no other suitable treatment is possible—e.g. medications such as Pulmicort® which can be used to treat allergic rhinitis and eosinophilic oesophagitis (**EoE**)**,** as well as asthma.
- Increase availability of carer payments for parents and carers of those with complex allergic disease, including access to a Health Care Card.
- Enable early referral to evidence-based credible support organisations, and increase their funding, in order to better meet the needs of people with allergic disease.
- Improve health professional education by utilising free e-training developed by ASCIA and health professional courses developed through Western Sydney University and the University of Adelaide. ASCIA also has a face-to-face course available for dietitians.
- Implement the National Allergy Strategy shared care model scoping project recommendations.

- Improve the use of telehealth for those in rural/remote areas.

- Expedite the PBS listing of allergic disease treatments used successfully overseas when there is no other comparable medication available in Australia.

- Make an alternative adrenaline autoinjector available to Australians with potentially life-threatening allergy. Serious consideration needs to be given to the doses available (i.e. is there a dose for infants or a dose for those 60 kg and over?), the size and shape of the device and how easily it can be carried (especially by males, who do not generally carry hand bags), needle length (shorter needles may not penetrate into the muscle for quick absorption of adrenaline), and temperature control in Australia's hot climate.

Term of reference 5—Developments in research into allergy and anaphylaxis including prevention, causes, treatment and emerging treatments (such as oral immunotherapy)

- Fast-track further research into possible treatments for food allergy.

- Support additional research into areas identified by A&AA in response to this term of reference as detailed in 8.2.

Term of reference 6—Unscientific diagnosis and treatments being recommended and used by some consumers

- Improve monitoring and investigation of alternative therapies that make unsubstantiated claims about diagnosis, management and treatment of allergic disease.

- Fund A&AA to develop and run a professionally moderated community forum for evidence-based sharing of daily allergy management of food allergy.

Term of reference 7—The impact of unnecessary drug avoidance due to unconfirmed drug allergies and its management, such as drug allergy 'de-labelling'

- Increase funding for a national coordinated drug allergy de-labelling project as detailed in the NAS outcomes of the Drug Allergy scoping project.

- Develop computer software that captures important information, including drug allergies, so that the most current information on drug allergy status is communicated with all health professionals involved in an individual's care.

3. Background to submission

3.1 Who we are: Allergy & Anaphylaxis Australia (A&AA)

A&AA is a national charity supporting and advocating for people with allergic disease in Australia. The charity has existed since 1993 and is recognised as a Peak Health Advisory Body by the Australian Government Department of Health.

We have a Medical Advisory Board and work in partnership the Australasian Society of Clinical Immunology and Allergy (**ASCIA**), through the National Allergy Strategy (**NAS**). A&AA and ASCIA partnered, developed and launched the NAS in collaboration with other key stakeholder organisations in 2015. Projects to date include: food allergy prevention; 250K youth; food service; shared care model scoping; anaphylaxis register; drug allergy scoping and more.[1]

A&AA Vision: Improved quality of life for all Australians living with allergic disease.

A&AA Mission: The trusted charity for allergy support. We listen, guide and educate Australians living with allergic disease. We advocate on their behalf to ensure their voice is heard.

3.2 Introductory comments about allergic disease

The term allergic disease covers several disease states, including but not limited to, atopic dermatitis (eczema), allergic rhinitis (hay fever), allergic asthma, food allergy (including mammalian meat allergy), drug allergy, latex allergy, insect allergy (including tick allergy), exercise induced anaphylaxis (often food dependant), idiopathic anaphylaxis (no known cause) and cold urticaria. Allergic disease currently affects more than 4 million Australians and is rising in prevalence. It impacts on quality of life, and those with multiple or severe disease states, or that live with the risk of anaphylaxis have a greater burden.

For someone with a severe allergy, exposure to an allergen can cause a life-threatening reaction called anaphylaxis. This reaction commonly affects several body systems, often within minutes of exposure to the allergen. Anaphylaxis involves the respiratory system and/or the cardiovascular system. Gastrointestinal symptoms however are also a marker of insect anaphylaxis. Not all people with an allergy are at risk of anaphylaxis.

For the most part, allergic disease is chronic and has no cure. Many Australians have more than one allergic disease state and many families have several family members with allergic disease. A parental history (i.e. both parents) of allergic disease equates to offspring having a 60% chance of developing allergic disease. Allergic diseases do not take hold because of poor decision making. Food allergy is not a lifestyle choice.

Many individuals have complex allergic disease. Complex disease decreases quality of life and increases the burden on the health system, with patients needing to see specialists more often as their disease states are more challenging and often difficult to control in everyday life.

It is A&AA's belief that early connection with our organisation gives individuals and parents the best opportunity at developing a balanced approach to severe allergy management, especially when someone is at risk of anaphylaxis. A&AA is evidence-based, has a medical advisory board and is closely aligned with the peak medical body (ASCIA). Most staff working at A&AA live with severe allergy and we employ three part time health professionals answering our national telephone support line, responding to enquiries, managing social media and creating resources. A&AA is therefore well placed to provide optimum support and education through the patient journey.

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[1] For more information about the NAS, see https://www.nationalallergystrategy.org.au/.

3.3 Growing demand for support for those with allergic disease

A&AA has made strong progress in achieving its vision and mission. The growing demand for our services is evidence of A&AA's increasing reputation and reach. In 2017 we moved to a free membership model as most of those who were reaching out for support were not members. We felt the small membership fee was an obstacle to some having evidence based, current information. A&AA's biggest challenge is resourcing. Increased funding of A&AA to be able to continue to support those with allergic disease, and the critical work of the NAS is essential. The NAS requires funding to continue to achieve key goals in improving healthcare as does ASCIA to maintain free access to credible e-training resources.

We are the trusted hub for information on allergic disease, especially for those at risk of anaphylaxis, and those that have complex allergic disease. However, it is not only individuals and parents that we support, educate, inform and assist. Health professionals, workplaces, school and childcare staff, food industry, community groups, government and others access our information and often need our assistance with information on accurate diagnosis, timely access to care, reasonable daily management strategies and emergency treatment. A&AA is represented on many state and federal government working parties and collaborations striving to improve health and wellbeing of those with allergic disease. These include but are not limited to Food Standards Australia New Zealand (**FSANZ**) Allergen Collaboration and Codex working groups, the Allergen Bureau, the Australian Food and Grocery Council (**AFGC**), Therapeutic Goods Administration (**TGA**) and Consumer Healthcare Products Australia.

There is much to be done, and A&AA strives to work on areas of highest need, while building financial sustainability. Sustainable funding to allow us to continue to grow our team and our reach is critical if we are to continue to meet the needs of those we support. As a Peak Health Advisory Body we receive some funding from the Australian Government Department of Health. However, as previously raised with the Hon Greg Hunt, Minister for Health, current funding levels are not adequate to ensure service delivery for the growing number of Australians with allergic disease.

The increasing call on our services, our media presence and our activity demonstrates our reputation as the trusted charity for allergy support. Below is an example of the growth in A&AA's online presence:

Website Visits	**Page Visits**
January - June 2016 : 29,387 compared with January - June 2019: 146,455	January - June 2016 : 106,490 compared with January – June 2019: 581,256
Growth: 398%	Growth: 446%

Further information about the increase in demand for A&AA's services is in **Annexure A**.

4. A&AA submission and recommendations - term of reference 1

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

A&AA refers to the NAS submission, which was prepared in partnership by ASCIA and A&AA. In addition to the NAS submission, A&AA would like to discuss the following:

- deaths from anaphylaxis; and
- the need for an anaphylaxis register.

4.1 Deaths from anaphylaxis

A&AA believes that lack of allergist involvement in ongoing care when someone is at risk of anaphylaxis to food or insect increases the risk of catastrophic outcomes, as does not belonging to a credible support organisation. In our experience, almost all who die as a result of anaphylaxis are not under the ongoing care of an allergist. A&AA believes that people belonging to support organisations are better informed about management and emergency treatment. Some people with severe allergic disease have never seen or only seen an allergist only once in their allergy journey. Seeing an allergist annually or every second year, means current allergic status, risk of anaphylaxis, management, latest treatments and emergency treatment are regularly discussed.

After the deaths of several individuals over the last 20 year period, A&AA has spoken (with permission) with allergists about the medical history of other family members. As a result, these families were expedited to see an allergist and all of those referred by A&AA now have other family members diagnosed with potentially life threatening allergy. These individuals have been prescribed an adrenaline autoinjector and educated on management.

To reduce deaths occurring from anaphylaxis, increased education of the community about the severity of allergic reactions and the potential for a severe reaction resulting in death is essential. This must be done in a way that informs and empowers the community rather than escalates anxiety. There are many helpful resources developed by A&AA, ASCIA, NAS and paediatric hospitals with allergy clinics, however many are not aware of their existence.

A&AA recommendations:

- ***Improve community education by increasing the sharing of freely available educational information through ASCIA, A&AA and the NAS.***
- ***Refer at-risk individuals to an allergist and an evidence-based national patient support organisation, such as A&AA.***

4.2 A national anaphylaxis register

There have been a small number of coronial investigations into deaths from food allergy. A&AA has been involved in nine and called as an expert witness in several coronial inquests. These investigations have helped inform A&AA's work and improve allergy management and safety.[2] The learnings from coronial investigations cannot be underestimated and where possible we would encourage greater coronial investigation of deaths from food allergy, most of which could have been prevented.

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[2] Information about coronial inquest findings and recommendations can be found here: https://allergyfacts.org.au/news-alerts/coronial-inquiry.

A number of coroners have recommended the establishment of an anaphylaxis register.[3] We believe that the systematic reporting of anaphylaxis events will allow the identification of high risk groups, specific risk factors, gaps in knowledge and care, possible policy development and provide an opportunity for improved reporting, investigation and compliance of the food industry. The information that is gathered will allow prevention and education programs to be tailored to the community's needs and the data will enable patient focused research.

The NAS is currently seeking key stakeholder input on a national anaphylaxis register that would capture all anaphylaxis presentations to/in hospitals and all fatalities. This register would enable us to better understand management and emergency treatment and assist us in improving care for those at risk of anaphylaxis.

A&AA applauds the Victorian state government on the 2018 launch of a data collection system capturing anaphylaxis presentations to hospital emergency departments (**ED**). This initiative is in response to a recommendation from the Ronak Warty inquest to assist with prompt investigations when packaged food and/or food service establishments have been implicated. A&AA sees this as a first step, as the reporting system only includes presentations to emergency departments (not in hospital anaphylaxis or other health facility presentations that are not sent to ED) and does not capture those that die once they are moved to an intensive care unit from ED.

A&AA recommendations:

- ***Establish state-based registers to allow systematic reporting of anaphylaxis events that can then be de-identified and compiled to form a national register.***
- ***Require all deaths from anaphylaxis or suspected anaphylaxis to be reported to the coroner and increase the number of coronial inquests into deaths from anaphylaxis, particularly where the inquest is likely to facilitate an understanding of allergy management and improved safety.***

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[3] See recommendations from the Inquest into the death of Hamidur Rahman, Inquest into the death of Alex Baptist and Inquest into the death of Ronak Warty. These are available at https://allergyfacts.org.au/news-alerts/coronial-inquiry.

5. A&AA submission and recommendations - term of reference 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);

5.1 Food labelling

A&AA has worked on food allergy and safety with lead organisations including FSANZ**,** the AFGC, the Allergen Bureau, the Food and Beverage Importers Association, state food units, the Allergen Collaboration and others for many years. These entities have worked tirelessly with A&AA and progressed many initiatives to assist both industry and consumers. A&AA is grateful for the work done to improve safety to date however more needs to be done.

There is a great need to ensure food importers, ingredient suppliers, manufacturers, regulators, compliance officers and all working in food production understand their responsibilities in food allergen management. Accurate food labelling that is clear and consistent is critical so that consumers with food allergy can make safe and informed decisions about the foods they purchase. Unfortunately food recalls due to undeclared allergens are increasing, with allergen recalls being the reason for the majority of recalls.[4]

While A&AA welcomes and is grateful for the work FSANZ is progressing on Plain English Allergen Labelling, an ongoing challenge for consumers is precautionary allergen labelling (**PAL**) which is currently voluntary. There is no universal terminology used to communicate cross contamination (when an allergen is unintentionally part of a food product). PAL statements vary widely. Some of the terms used by packaged food manufacturers include ‘may contain traces’, ‘may contain’, ‘contains traces’, ‘may be present’, ‘made in a facility’, ‘processed on a production line’ etc. Consumers wrongly believe each term is related to a level of risk. There remains much confusion in the community around labelling requirements, with a Melbourne study recording that up to 80% of parents whose children are at-risk of anaphylaxis thought PAL was unhelpful, with many ignoring such statements.[5]

Despite the development of the Allergen Bureau Voluntary Incidental Trace Allergen Labelling (**VITAL**) process 12 years ago which recommended a specific process for decision making on whether a product needed a PAL statement and then use of the term ‘may be present’ when a food poses risk to someone with food allergy[6], this system is not widely used or reflected on pack and remains voluntary. Whilst a VITAL Standard was released in October 2019 and there is now the ability for a manufacturer to place a VITAL symbol on pack near the ingredient list to show a product has been labelled according to the single rigorous VITAL process, the use of VITAL remains voluntary and the use of the symbol on pack remains voluntary. Currently consumers cannot be confident that a product without a PAL statement can be trusted, however if the new VITAL symbol IS on pack this will improve confidence in the information on pack whether it has a PAL statement or not.

Other issues include parallel imported foods available for purchase side by side containing differing ingredients,[7] changes to the allergen content of packaged foods,[8] product families

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[4] Food recall data is available from Food Standards Australia, see: http://www.foodstandards.gov.au/industry/foodrecalls/recallstats/Pages/default.aspx

[5] https://www.mja.com.au/journal/2013/198/11/perceptions-precautionary-labelling-among-parents-children-food-allergy-and

[6] For more information about VITAL, see http://allergenbureau.net/vital/.

[7] A recent example involved Sakata crackers. The Australian manufactured crackers contained sesame and the same product manufactured in Cambodia did not contain sesame.

[8] A&AA encourages consumers to read food labels every time a product is purchased because of the risk of manufacturers changing ingredients in the product. In addition, having the same products with differing allergen content on the shelf at the same time is a safety issue. A&AA encourages manufacturers to alert consumers to

with similar looking products with varying allergen content[9] and a general lack of understanding of reporting requirements where allergic reactions occur.

A&AA recommendations:

- ***Mandate precautionary allergen labelling alongside the Voluntary Incidental Trace Allergen Labelling (VITAL) process, including the VITAL Standard and the VITAL symbol on packaging, so that people can have clarity and confidence in the allergen information shared on packaging.***
- ***Require food manufacturers to communicate changes in allergen ingredients on the front of a pack and also alert national support organisations, such as A&AA, of the change. If the old and new products are on the shelf at the same time, this also needs to be communicated.***
- ***Encourage food manufacturers to consider food allergy when creating families of products, different size packs of the same products, and different versions of products that have different allergen content by communicating this on packaging, differentiating packs, and sending alerts to A&AA to share with consumers managing food allergy.***
- ***Translate the Food Standards Code (FSC) and other relevant guides into the most common languages so business-owners from culturally and linguistically diverse backgrounds or those with low English literacy have access to legislative requirements and best practice guidelines around labelling of packaged food made in and imported into Australia. Translations would also assist the food service industry.***

5.2 Food Service

Most food anaphylaxis in early childhood occurs at home. Outside the 0-4 age range, anaphylaxis often occurs as a result of food eaten away from home. Fatalities from food allergy often occur as a result of food eaten away from home.

When people with food allergy disclose their allergy clearly to a food service provider, they need to be able to trust that the people preparing and serving their food understand the seriousness of food allergy and the risk of anaphylaxis. Once an allergy is disclosed, food served to a customer must not contain the allergen as an ingredient and care should be taken to prevent cross contamination. To achieve this, food service establishments must have appropriate training and strategies in place. In our experience, some establishments have trained staff who have a good understanding of food allergy, listen carefully to customer requests and follow procedures to reduce risk, others have no understanding of food allergy and risks to the consumer. This is despite legislation that has existed for many years.

Other high risk areas include:

- school camps, wedding receptions and workplace functions;
- online ordering for groceries and take away food where these websites and apps are not adequately designed to capture and alert staff to food allergies, and

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allergen changes on front of pack and to also alert A&AA to the change so we can alert consumers. An example of such an alert is available here: https://allergyfacts.org.au/news-alerts/food-alerts.

[9] Having food packs containing similar foods with different ingredients that look almost identical is a danger to those with food allergy even when the product is appropriately labelled. Whilst it is the individual's/parent's/carer's responsibility to read the ingredient information every time a food is purchased, A&AA believes that packs of like products containing different allergens should be more easily distinguished. Manufacturers need to give this issue serious consideration to help reduce the risk of mistakes. This would be an additional safeguard for those with food allergy.

consumers do not speak directly to those preparing their food or cannot view product labels. We are aware of inappropriate food substitutions that have been made and errors because of lack of training and protocols in place; and

- hospital and other institutional food service settings. In particular where meals are prepared offsite and where those serving food have not been involved in food preparation. We are aware of one death in a hospital setting as a result food anaphylaxis and then development of an anaesthetic complication.[10] In addition, A&AA frequently reports allergic reactions and near misses that occur in hospital settings to state health departments for investigation. Some allergic reactions have been averted (usually thanks to parental vigilance) whilst others have had potentially life threatening events.

State health departments and local councils investigate food allergen complaints in relation to food service. A&AA has developed a flow chart to assist individuals with lodging complaints.[11] A&AA lodges at least two complaints per week on behalf of consumers. Often these result in food recalls and investigation of food service establishments.

In our experience, investigations of food allergy complaints vary and depend on the knowledge and expertise of environmental health officers. A&AA is concerned about the unwillingness of some officers to investigate food allergy complaints (including when a product has a PAL statement) and the lack of understanding of others about labelling requirements.

Fatalities in food service are often investigated by police and not state health department food compliance officers. Investigation by experts in food safety, including food allergy, would assist in progressing investigations which sometimes result in coronial investigations, enforcement of food safety laws and civil prosecutions.

A&AA recommendations:

- ***Improve community education on eating away from home with food allergy and risk reduction for online ordering for individuals and their carers.***
- ***Require anyone working in food service to successfully complete the basic free National Allergy Strategy 'All About Allergens' e-training (similar to the Responsible Service of Alcohol certificate for those working in licenced premises).***
- ***Require every food service facility across Australia to have a Food Safety Supervisor trained in food allergy.***
- ***Translate food legislation and guides into languages other than English to assist food service proprietors and staff.***
- ***Improve education and audit tools for environmental health officers by including information on food allergy management in food service.***

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[10] For more information see the Finding into the Death of Louis Oliver Tate which is available at https://allergyfacts.org.au/images/Finding_into_Death_with_Inquest_-_Louis_Oliver_Tate_08.05.18_web2.pdf.

[11] See https://allergyfacts.org.au/allergy-management/risk/reporting-an-allergic-reaction.

6. A&AA submission and recommendations - term of reference 3

The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis;

6.1 Increased training of health professionals

Health professionals are keen to know and understand more about allergic disease.

ASCIA, the NAS and A&AA have attended and presented at many health professional workshops, seminars, dinner meetings etc. Research conducted by TKW Health on behalf of Allergy & Anaphylaxis Australia among 150 Australian GPs in March 2019 showed nearly three quarters of GPs (74%) would like a better understanding of food allergy. Attendance and interest at the educational events reflect this survey finding.

It is A&AA's view that many GPs do not have confidence in food allergy diagnosis and management, whilst others order diagnostic investigations that are not required and can be incorrectly interpreted. Reliance on diagnostic tests without a thorough history being taken by a well-informed health professional can lead to inaccurate diagnosis and advice being given to a patient. This sometimes results in unnecessary food restrictions and inappropriate management strategies that can impact on growth, nutrition and quality of life. A&AA is also aware of health professionals in primary care deterring people from seeing a specialist because wait lists are too long.

In addition, the increase in prevalence and complexity of child and adult allergic disease in Australia means that more allergy specialists (and other health professionals with specific allergy knowledge) are required, including in regional areas. Many individuals in rural or remote areas often have no access to specialists unless they travel long distances (after a long wait time) as most allergy specialists consult in capital cities. Health professionals, including doctors, nurses, dietitians and psychologists that do not have allergy specific knowledge and expertise may struggle to care for individuals in line with best practice and may not appropriately refer individuals in a timely manner. Whilst ASCIA has developed free education and training packages for a variety of health professionals, A&AA is aware of many individuals being given advice that is not evidence based and does not follow current best practice. It is vital that people have trust in their treating health professionals as this allows them to best manage their allergic disease.

Other specific areas of need for health professional education are included in **Annexure B**.

A&AA recommendations:

- ***Increase the education component in health professional training on allergic disease.***
- ***Increase the number of training positions for allergy specialists.***
- ***Increase awareness among health professionals of current freely available resources, including e-training.***
- ***Fund ASCIA to provide free e-training courses, including Continued Professional Development (CPD) points for health professional training courses.***
- ***Improve support for general practitioners (GPs) to increase their allergy awareness and skills (consider a mentor system with an allergist/allergy clinic).***
- ***Increase use of telehealth to connect rural and remote patients to allergists.***

6.2 National clinical care standard for anaphylaxis

Anaphylaxis is a potentially life threatening allergic reaction. Despite this, there is currently no national clinical care standard for anaphylaxis. A&AA understands that some health professionals, including paramedics, general practitioners and doctors working in emergency departments are treating anaphylaxis using antihistamines and/or nebulised adrenaline and asthma medication, and/or corticosteroids without use of intramuscular adrenaline. This practice is not only against current best practice, it also teaches patients and carers to avoid giving adrenaline in an emergency.

In Victoria, a state based clinical care standard has been released by Safer Care Victoria. However, A&AA is aware of anaphylaxis emergency treatment in Victorian health care facilities still not following the standard, so it is essential that implementation of the standard is monitored and audited.

Patients that have experienced anaphylaxis continue to report anaphylaxis being treated with medications other than intramuscular adrenaline or that intramuscular adrenaline is not used as the first emergency treatment. We continue to hear of patients being walked into an ambulance or into hospital when we know upright posture can cause sudden drop in blood pressure and collapse. This is despite the patient's ASCIA Action Plan (a medical document signed by their treating doctor) stating the individual must not stand or walk once adrenaline is administered.

A&AA recommendation:

- ***Develop and roll out a national clinical care standard for anaphylaxis.***

6.3 School/childcare management of severe allergy

Allergic reactions to foods often occur in schools and children's services. These are generally as a result of communication breakdown, policies not being implemented and food service staff not being trained in food allergy (e.g. a child with cow's milk protein allergy given lactose free milk).[12]

There is a need for national minimum standards for schools and early children's services to address:

- the requirement to have individualised health care plans which include age appropriate strategies to reduce the risk of allergic reactions including anaphylaxis;
- inconsistencies between state and territory based guidelines, policies, procedures and legislation including in relation to the number of staff to be trained in anaphylaxis management at childcare centres and anaphylaxis training for school teachers;[13]

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[12] Lactose free milk contains cow's milk protein and cannot be given to a child with cow's milk protein allergy.

[13] For early children's services: Alarmingly, current childcare anaphylaxis regulation through Australian Children's Education and Care Quality Authority (**ACECQA**) requires only one staff member to be trained. This was despite A&AA's recommendation to ACECQA at the time the regulation was being developed that all staff need to be trained in recognition, management and emergency treatment of anaphylaxis. This is a safer approach for the child but also means staff have support in an emergency as other staff are also trained.

For schools: Some states including NSW and Victoria requiring staff to do ASCIA e-training every 2 years while Western Australia requires teacher ASCIA e-training every 3 years. Victoria, through ministerial order 706, has legislation around anaphylaxis training and management while NSW has 'procedures' and other states have policies or guidelines. Some states require the majority of staff to be trained whilst others state the number is at the principal's discretion. All NSW staff (permanent, temporary and casual) working in NSW Department of Education schools must do ASCIA anaphylaxis e-training.

- the lack of a consistent requirement for all early children's services and schools (including state, independent and Catholic) to have adrenaline autoinjectors in their first aid kits as a back-up device for those already diagnosed or if needed for an individual not previously diagnosed with severe allergy;
- education of the student and parent community using resources currently available through A&AA[14], initiatives such as Food Allergy Week and school publications;
- policies and procedures around school camps and special events including excursions, which are particularly high risk, with allergic reactions regularly being reported to health departments across the country;
- awareness of allergy in school settings and reducing bullying of students at risk of anaphylaxis; and
- appropriate management of food allergy for high school students who are at higher risk of fatal anaphylaxis.

A&AA recommendations:

- ***Adopt and implement national minimum standards for food allergy and anaphylaxis management (developed by the National Allergy Strategy in consultation with key stakeholders) in schools and early childhood services.***
- ***ALL schools and early childhood services provide Adrenaline autoinjectors for general use in first aid kits.***

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[14] These resources are currently being updated as part of a NAS project. See https://allergyfacts.org.au/allergy-management/5-12-years/primary-school-resources and https://allergyfacts.org.au/allergy-management/13-18-years/high-school-resources.

7. A&AA submission and recommendation - term of reference 4

Access to and cost of services, including diagnosis, testing, management, treatment and support;

7.1 Significant cost burden of allergic disease

The prevalence and cost burden of allergic disease in Australia is significant. Unlike many disease states, allergic disease includes a number of allergic conditions. Many in the community, including several within one family, may have a combination of diseases that require daily medications to prevent exacerbations and treat ongoing symptoms. Allergic disease is a chronic disease that for the most part, cannot be cured.

Medications used to manage allergic disease are rarely subsidised by the Pharmaceutical Benefits Scheme (**PBS**) and this adds to the cost burden of affected individuals and families. Many of these medications and treatments are purchased over the counter without a prescription. The cost of nasal sprays, sinus rinses, antihistamines, moisturisers, topical corticosteroids, asthma preventer and reliever medications, oral steroids, non-soap washes/shampoos etc are a huge burden on people with allergic disease. Some medications for allergic disease are only PBS listed for one allergic disease state but not for others and this too is an added frustration for those with extreme cost burden to manage their/their family's health condition. A table showing possible costs for one example family with allergic disease is included as **Annexure C**.

In addition to the cost of regular visits to specialists, children and adults living with severe allergic disease often experience anxiety that is related to their condition and require psychological services. While some of the cost of psychological services may be covered by a mental health care plan, only a portion of professional fees are covered and out of pocket costs add to the financial burden of living with allergic disease. The cost of these services can be crippling for individuals and families while others just cannot access them. Being at risk of anaphylaxis results in some people withdrawing from society, the workforce, and even school with some parents' (almost always unnecessarily) home schooling because of the risk.

In addition, people with food allergy, especially those with milk, egg, wheat allergy and those with multiple food allergy often have to buy food from the health food aisle. This food is more expensive and therefore another significant added cost to people living with food allergy.

Only a small number of individuals can currently access a healthcare card or carer payment to assist with the costs of managing severe allergies. People with allergic disease do not cause their allergic disease to happen. This must be a consideration when reviewing the challenges allergic diseases pose.

A&AA recommendations:

- ***Increase subsidies for medications used to prevent and treat allergic disease.***
- ***Subsidise medication for people with more than one allergic condition to reduce the financial stress of allergic disease.***
- ***Subsidise existing subsidised medications used to treat one allergic condition for use with other allergic conditions where no other suitable treatment is possible—e.g. medications such as Pulmicort® which can be used to treat allergic rhinitis and eosinophilic oesophagitis (EoE), as well as asthma.***
- ***Increase availability of carer payments for parents and carers of those with complex allergic disease, including access to a Health Care Card.***

7.2 Access to specialist allergy care

Access to allergy specialist care is often delayed because of long wait lists and a lack of specialists outside of capital cities. Individuals with severe allergic disease need to manage their condition daily whilst waiting to see a specialist. This time of uncertainty and (often) lack of support and information, breeds fear and anxiety. Many health professionals do not have a depth of knowledge of some allergic disease states such as food allergy and this further compounds the challenge of not enough allergy specialists and a small number of public allergy clinics with long waiting lists.

Access to care for those in rural/remote areas is even more problematic with many not able to access appropriate, let alone optimal healthcare. The Northern Territory does not have an allergist although at least two allergists visit Darwin for a day of consults infrequently.

Challenges accessing specialist allergy care also:

- delays diagnosis and education of patients. Accurate diagnosis and education on reasonable risk minimisation strategies is critical. The “limbo” time between reaction and appointment is a time where patients can develop anxiety, unnecessarily restrictive or conversely dangerous behaviours. Young babies need to be prioritised. A twelve month wait for these babies means the child is over a year old and common allergens (other than the one that triggered the reaction) are not introduced into the diet because of fear of another allergic reaction. Current published research encourages introduction and continued consumption of common food allergens (i.e. peanut and egg) before the age of twelve months to reduce the likelihood of development of food allergy;[15]

- results in some individuals seeking advice from alternate practitioners. As people are desperate for information on diagnosis and every day management they often seek advice from alternate practitioners and undergo unproven testing/treatments for varying allergic disease states including food allergy. There are also many social media sites including bloggers who contribute to misinformation and even scare mongering by disseminating information that is often not evidence based, inaccurate and sometimes dangerous. It is difficult for someone starting their allergy journey to decipher myths from facts;

- means that many adults with moderate to severe allergic disease are not under the care of a specialist, not properly diagnosed or treated, not prescribed an adrenaline autoinjector (if indicated) or educated about allergen avoidance and emergency treatment (if indicated);

- means that those with serious allergic disease who are not at risk of anaphylaxis go to the bottom of public allergy clinic waiting lists. This is often to the detriment of the patient who could benefit from allergy specialist opinion/discussion (for example about immunotherapy for environmental allergens to decrease severity of allergic rhinitis); and

- reduces the number of food and drug clinics and challenges available. Confirmation of a true food or drug allergy is critical from a safety perspective and removal of a label of food/drug allergy greatly benefits the consumer and decreases the burden on the healthcare system. Many are currently waiting years for a food/drug challenge.

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[15] For more information about the timing of introduction of allergenic foods to babies, see https://preventallergies.org.au/

A&AA believes that early referral to an evidence based support organisation with a medical advisory board and staff that are health professionals and live life with allergic disease would assist individuals whilst waiting for allergy specialist consult and then as they progress through their journey with conditions such as food allergy, allergic rhinitis and atopic dermatitis (eczema).

A&AA recommendations:

- ***Enable early referral to evidence-based credible support organisations, and increase their funding, in order to better meet the needs of people with allergic disease.***
- ***Improve health professional education by utilising free e-training developed by ASCIA and health professional courses developed through Western Sydney University and the University of Adelaide. ASCIA also has a face-to-face course available for dietitians.***
- ***Implement the National Allergy Strategy shared care model scoping project recommendations.***
- ***Improve the use of telehealth for those in rural/remote areas.***

7.3 Specific challenges for complex and severe allergic disease, including immunoglobulin E (IgE) and non-immunoglobulin E (non IgE) mediated food allergy, atopic dermatitis, insect allergy and allergic rhinitis

Those with complex/severe allergic disease such as those with IgE and non IgE mediated food allergy are often under several specialists as well as their GP and dietitian and sometimes a psychologist. Communication between the medical team is often lacking because of workload and incompatible software/communication systems and this requires the individual/parent to chase medical reports to share with all health professionals involved in the individual's care. This adds to the burden of management with the parent/individual feeling disillusioned in the healthcare system and how it operates.

An added burden is difficulty in accessing long awaited new treatments. Some with severe allergic conditions such as severe atopic dermatitis have lost hope that their lives will ever change because they have exhausted treatment possibilities. These patients often lose hope, sometimes stop seeking specialist care and often live in isolation. New medications such as Dupilumab® are literally a life-line for some patients with severe allergic disease and these should be expedited and not have to go through the current elongated Pharmaceutical Benefits Advisory Committee (**PBAC**) process as this further impacts quality of life when all other options have been exhausted.

A&AA has prepared information about the specific challenges of living with non IgE mediated food allergy, atopic dermatitis (eczema), insect allergy and allergic rhinitis (hay fever). This information is in **Annexure D**.

A&AA recommendation:

- ***Expedite PBS listing of allergic disease treatments used overseas with great success when there is no other comparable medication available in Australia.***

7.4 Adrenaline autoinjectors

Currently, Australia only has one brand of adrenaline autoinjector (EpiPen®). There have been several EpiPen® shortages with the most significant being in 2017/2018.The impact on individuals at risk of anaphylaxis, A&AA, ASCIA, the Therapeutic Goods Administration, pharmacies and Mylan Australia was huge. The safety of individuals at risk of anaphylaxis was compromised with people being asked to rely on expired devices, parents and childcare staff not giving the EpiPen® when indicated because of fear they would not be able to replace it and ill-informed health professionals showing people how to use ampoule, needle and syringe.

A&AA recommendation:

- ***Make an alternative adrenaline autoinjector available to Australians with potentially life-threatening allergy. Serious consideration needs to be given to the doses available (i.e. is there a dose for infants or a dose for those 60 kg and over?), the size and shape of the device and how easily it can be carried (especially by males, who do not generally carry hand bags), needle length (shorter needles may not penetrate into the muscle for quick absorption of adrenaline), and temperature control in Australia's hot climate.***

8. A&AA submission and recommendations - term of reference 5

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

8.1 Food allergy treatments, including oral immunotherapy

There is no current cure for food allergy. The only way for an individual to prevent an allergic reaction is avoidance of the food.

Australia has several current research trials into possible treatments (not cures) for food allergy. This research is being done in allergy clinics across Australia. Treatments for food allergy, such as oral immunotherapy (**OIT**), have been challenging, as the risk of anaphylaxis whilst progressing the treatment is significant. The peanut patch, probiotics or other adjuvants with OIT and the peanut vaccine are other currently researched treatments that aim to increase the amount of peanut an individual can tolerate. The above are still years away from being registered treatments.[16]

While ASCIA currently advises that OIT is a treatment that is still being researched, A&AA has become aware of a small number of Australian doctors (allergists and other medical practitioners) progressing OIT in their rooms rather than a hospital setting outside of research studies. We are also aware of a number of people going to the United States of America, Singapore and Hong Kong to access OIT outside of hospital based research trials.

Some people are critical of the fact Australia does not have OIT as a treatment however others report they do not see how OIT would improve their lives if they have to rest for 2-3 hours after every daily dose of allergen, still have to avoid the allergen throughout the rest of the day (unless resting for 2-3 hours afterwards) and still have to carry an adrenaline autoinjector. The risk of developing other non-immunoglobulin E (IgE) mediated food allergy (such as Eosinophilic Oesophagitis) when starting OIT (which some say have an even greater impact on quality of life) needs further consideration, discussion and research.

A&AA is concerned about the current access to optimal care in Australia. Waiting lists for public allergy clinics are long and some allergists advise return appointments several years apart because of long waiting lists. Prior to commencing a food allergy treatment (such as OIT) the patient should undergo a food challenge to ensure that the patient is truly allergic before treatment commences. Public allergy clinics are already overwhelmed with the number of individuals requiring food challenges. It is imperative that any treatment for food allergy which is not a cure, does not worsen wait list times, therefore further delaying access to timely diagnosis, education on management and emergency treatment and food challenges.

With the above considerations in mind, it is important for Australians to be able to make informed choices on emerging treatments. The safety of the individual must be kept top of mind, as must ethical issues relating to parents making decisions on children undergoing treatments for foods the child may well naturally outgrow. If the child is not afforded the opportunity to naturally outgrow the allergen will they need to be on OIT, still avoid the food allergen outside their daily dose and carry an adrenaline autoinjector for life? Clinicians and parents must also consider the reality of increased allergic reactions, including anaphylaxis, when on OIT for food allergy. A recent systematic review and meta-analysis showed that there were three times more allergic reactions requiring adrenaline (anaphylaxis) while patients were

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[16] The peanut vaccine uses selected fragments of peanut proteins to switch off allergic responses without involving the peanut proteins that cause the life-threatening reactions. Unlike other potential treatments, this vaccine would not need life-long daily dosing. A current research study looking at high doses of probiotic use and peanut OIT is looking promising with a small number of individuals already studied now eating peanut freely (or not), without restriction/instruction on dosing etc. Viaskin® peanut patch increases the amount of peanut a child can tolerate with minimal risk of progression to anaphylaxis. This helps prevent anaphylaxis as a result of accidental exposure.

on OIT than those avoiding the allergen (status quo). Quality of life of was not improved on the treatment.[17]

The spontaneity of teens and young adults should also be considered when parents start OIT in childhood not knowing how compliant with strict daily routines the teen will be, whether they will still disclose their allergy when eating away from home and continue to carry an adrenaline autoinjector. Parents need to be given all the information they need to make a decision on whether the treatment will improve their child's quality of life.

People need to have safe, affordable, manageable treatments available to them. Avoidance is difficult and greatly impacts on quality of life. However, A&AA has serious concerns about treatments that cause more allergic reactions than avoidance alone especially when progressed outside of research. A&AA believes that OIT needs further research and standardised approved protocols. Treatments currently being researched in Australia and overseas need to be supported and expedited (if possible). Some treatment options that pose potentially less risk and are less onerous on the health system may be a good option for some where avoidance alone is not manageable long-term.

A&AA recommendations:

- ***Fast-track further research into possible treatments for food allergy.***
- ***Support additional research into areas identified by A&AA in response to this term of reference as detailed in 8.2.***

8.2 Areas for further research

A&AA would welcome research in the following areas:

- quality of life; psychosocial aspects of having a life threatening allergy; recovering from a life threatening event;
- the risk of anaphylaxis from the touch, smell or airborne ingestion of food allergen. Many people are very concerned about the risk of anaphylaxis from touch, smell or airborne ingestion of a food allergen. Whilst there are some studies from the early 2000s it would be helpful to have recent research to investigate exposure to allergens other than through ingestion as this causes extreme fear and panic in many situations including in schools, planes and restaurants;
- fatal allergic reactions. Speaking to families that have lost loved ones can help us to further understand gaps in care and helps the majority of families feel their loss has not been in vain;
- improved diagnostic tools for allergic disease and prediction markers to indicate severity of anaphylaxis, who will outgrow food allergy etc;
- possible treatments for food allergy as above in 8.1;
- non IgE mediated food allergy. This is not well understood and further research is required to investigate prevalence, diagnosis, current treatments and ongoing pain which is not well understood;

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[17] See https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)30420-9/fulltexts.

- the number of doses of adrenaline required in an emergency. A&AA receives information from individuals and parents post anaphylaxis and many communicate that more than one dose of adrenaline is required in an emergency. Current Australian data on this issue would inform our advice to individuals on how many adrenaline autoinjectors they should carry with them at all times. As a child of 20kg has the same dose as an adult of 100kg, it is not surprising that we have more people communicating their experience of needing more than one dose. While an ambulance with more adrenaline on board may arrive in a timely manner, this cannot be relied upon even in city areas;

- prevalence data (for children **and adults**) on all allergic disease states including those at risk of anaphylaxis;

- manufacturer research into medication stability of adrenaline autoinjectors in climates that are often above 25 degrees Celsius.(The current adrenaline autoinjector should be kept away from direct sunlight and between 15-25 degrees Celsius. As temperatures in Australia are very often outside this range, more research into temperature fluctuations needs to be conducted to understand how heat may affect potency of adrenaline);

- the relationship between tick bites (and tick removal methods) and the development of mammalian meat allergy (**MMA**) and tick anaphylaxis, including prevalence of MMA in Australia. This research will help guide prevention, education and management of tick bite anaphylaxis and MMA; and

- patient management of atopic dermatitis and allergic rhinitis, including compliance with treatment regimes.

9. A&AA submission and recommendation - term of reference 6

Unscientific diagnosis and treatments being recommended and used by some consumers;

Even though there is no cure for allergic diseases, some impacted individuals/parents, driven to improve their quality of life and faced with long waiting lists to access specialists care, look for one. This may involve unorthodox approaches to care, non-evidence based information and expensive unproven tests. This advice can contribute to worse outcomes, unnecessary dietary restrictions, and delayed access to appropriate care and health risks associated with re-introduction of allergens after periods of avoidance.

Sometimes unproven methods/tests are used to diagnose allergies, including potentially life-threatening allergy. Test results can be interpreted incorrectly and other investigations progressed at a significant cost when they do not provide answers to help with improved quality of life and safety. Vulnerable people are often given advice that is detrimental to their health and further impacts quality of life. In addition, those seeing an alternative practitioner for severe allergy may not seek the care of an allergist.

The world of medicine has been significantly impacted by social media and the internet. Platforms such as Facebook chat groups about allergies provide a useful forum for consumers to benefit from the experience of others, however if these groups are not well managed and not evidence-based, they can give inaccurate and dangerous information leading to poor outcomes for followers.

A&AA recommendations:

- ***Improve monitoring and investigation of alternative therapies that make unsubstantiated claims about diagnosis, management and treatment of allergic disease.***

- ***Fund A&AA to develop and run a professionally moderated community forum for evidence-based sharing of daily allergy management of food allergy.***

10. A&AA submission and recommendation - term of reference 7

Term of reference 7: The impact of unnecessary drug avoidance due to unconfirmed drug allergies and its management, such drug allergy 'de-labelling'.

Drug/medication allergy incidence has increased in Australia, however consumer assumptions on symptoms experienced and doctor diagnosis do not always reflect the reality of a drug allergy. Generally, consumers and health professionals are not well informed about true drug allergy.

Accurate diagnosis of drug allergy can be difficult without adequate and skilled investigation. Health professionals are very aware of poor outcomes when an individual with true drug allergy has the medication, so they rarely question consumers who say they are allergic when they are not, for fear of getting it wrong. With antibiotic allergy, the truth around the label of antibiotic allergy is generally not questioned until a person is in a compromised situation where the drug of choice cannot be used.

A label of a medication allergy can limit treatment options at an increased cost and sometimes require drugs with greater risk of side effects/adverse outcomes. For example less desirable and less effective medications are often used for people with antibiotic allergy, which then affects health outcomes. It is important that medication allergies are confirmed (whether allergic or not) by experts so that individuals can receive optimal care with appropriate medications.

A&AA recommendations:

- ***Increase funding for a national coordinated drug allergy de-labelling project as detailed in the NAS outcomes of the Drug Allergy scoping project.***
- ***Develop computer software that captures important information, including drug allergies, so that the most current information on drug allergy status is communicated with all health professionals involved in an individual's care.***

Annexure A

	1 July 2018	30 June 2019	Growth
Facebook followers	38,603	48,028	24.4%
Average Telephone calls per month (over prior 12 months)*	353	374	5.9%
Website Visits (prior 6 months)	97,868	146,455	49.6%
Website Page Views (prior 6 months)	420,860	581,256	38.1%
Email Traffic Inbound and Outbound per month (over prior 12 months)*	6,191	7,451	20.3%

Annexure B

A&AA believes the following are areas of need for health professional education:

- The need for GPs to give adults an ASCIA Action Plan[18] when prescribing an adrenaline autoinjector (e.g. EpiPen®). An ASCIA Action plan, carried on the person with their adrenaline autoinjector, is best practice.

- Coordination of health care and patient education. A person with multiple allergies can often be under the care of multiple specialists and a GP. In our experience, often very little information and advice on food allergy management and emergency response is communicated to the patient unless the patient is under the care of an allergist or one of few paediatricians/GPs that have done additional training in allergic disease. The person's GP may think the specialist dermatologist, for example, is overseeing the food allergy diagnosis and management and the dermatologist thinks the GP oversees it as they are the ones providing a prescription for EpiPen®. This can leave patients without the tools they need to properly manage their allergy and respond appropriately to allergic reactions.

- Investigation of drug and medication allergy. Health professionals are aware of the poor outcomes when an individual with a true drug allergy has the medication that they are allergic to, so they rarely question consumers who say they are allergic to a medication when this may not be the case, for fear of getting it wrong. There is a critical need for education in the area of drug allergy so that those labelled with allergies to medications such as penicillin can be investigated and confirmed, or the label removed if the person is found not to be allergic.

- The need for those with allergy to be under the care of an allergist and newly diagnosed to be referred to a national evidence-based patient support organisation. A&AA believes that lack of allergist involvement in ongoing care increases the risk of catastrophic outcomes, as does not belonging to a support organisation (as we believe people belonging to support organisations are better informed about management).

- Appropriate use of corticosteroids and bleach baths to manage the risk of infection in patients with Atopic Dermatitis. A&AA is aware of instances of health professionals providing advice (for example to use steroid creams/ointments "sparingly)", rather than showing individuals how much to use.

- Appropriate referral of individuals with bee and wasp sting allergy to an allergist for immunotherapy (where appropriate) as desensitisation reduces the risk of anaphylaxis. This immunotherapy is subsidised for bee and wasp nationally and Jack jumper ant in Tasmania and Victoria where desensitisation clinics exist.

- Where appropriate, commencement of management of allergic rhinitis by a patient's GP, with referral to allergist only for moderate to severe allergic rhinitis. Those with moderate to severe allergic rhinitis should be referred to an allergist for further investigation and possible immunotherapy.

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[18] ASCIA Action Plans for anaphylaxis are available to view and download at https://www.allergy.org.au/hp/anaphylaxis/ascia-action-plan-for-anaphylaxis.

Annexure C

The below table outlines some of the estimated costs involved in allergic care for a fictional family of four living in a metropolitan area. The costs are estimates based on our experience assisting real families. Costs are before Medicare rebates (where applicable). With limited resources, we have done our best to include accurate Medicare rebate and PBS listing information however this should be confirmed with the Department of Health.

Mum - Allergic rhinitis - moderate

Treatment	Assumptions	Approximate cost (before Medicare rebate if applicable)	Approximate cost per annum (before Medicare rebate if applicable)	Medicare Rebate Applicable
Nasal steroid preventer (e.g. Nasonex®)	Nasonex® is over the counter	$25	$150	No
Antihistamine (eg Zyrtec®)	Zyretc® is over the counter. One tablet per day	$30 for 70 Zyrtec® tabs	$156	No
GP visit	3 allergy related visits	$80	$240	Yes
Dust mite bedding	Cost shared with Dad's bedding except pillow protector		$29 (approx. every 10 years)	No
TOTAL (before Medicare rebate if applicable)			**$575**	

Dad - Severe allergic rhinitis and well controlled asthma

Treatment	**Assumptions**	**Approximate cost (before Medicare rebate if applicable)**	**Approximate cost per annum (before Medicare rebate if applicable)**	**Medicare Rebate Applicable**
Allergist visit - private	One visit per year	$300	$300	Yes
Antihistamine (eg Zyrtec®)	Zyretc® is over the counter. One tablet per day	$30 for 70 Zyrtec® tabs	$156	No
Nasal corticosteroid preventer (e.g. Dymista®)	Available on prescription	$50	$300	No
Nasal rinse bottle	4x/year	$12	$48	No
Nasal rinse refills	3x/year	$20 for 100	$60	No
Asthma preventer (e.g. Flixotide® 120-doses)	Available on prescription	$43 *	$258	No
Asthma reliever (e.g. Ventolin® *)	Available over the counter or on prescription.	$8 *	$48	No – unless concession card/pensioner card
Asthma Spacer		$20	$20 (one off)	No
Allergen immunotherapy		$200 per month	$2400	No
Dust mite proof bedding	Queen size mattress cover, doona cover and pillow cover.		$423 (one off)	No
TOTAL (before Medicare rebate if applicable)			**$4013**	

Child 1 - severe eczema, and at risk of anaphylaxis to peanut, egg, milk

Treatment	Assumptions	Approximate cost (before Medicare rebate if applicable)	Approximate cost per annum (before Medicare rebate if applicable)	Medicare Rebate Applicable
GP visits	6 GP visits per year related to allergies	$80	$480	Yes
Soap-free wash	E.g. QV wash	$22 1L	$264	No
Soap free shampoo	E.g. QV Shampoo	$10	$60	No
Soap free conditioner	E.g. QV conditioner	$10	$60	No
Soap free intensive moisturiser	E.g. QV Intensive;1 pump pack per week	$22 (500g)	$1,144	No
Bath oil	E.g. QV Bath Oil; 5 per annum	$20 1L	$100	No
EpiPen® prescription *	2 EpiPen®s available on authority script. No PBS available on supplementary EpiPen®s	$40 (on PBS) plus $100 for supplementary EpiPen® for after school care	$140	Not for EpiPen® outside PBS limit of 2.
Specialist foods (e.g. egg replacer, milk substitutes)			$500	No
Dietary supplement (e.g. calcium due to milk allergy)		Calcium supplement 50 tabs 2/day. $12	$84	No
Steroid ointment – body (e.g. Eleuphrat® *)	Authority Prescription.	$10 /15g 1 per week	$520	No Medicare benefit unless chronic condition.
Steroid ointment – face (e.g. Elidel® *)	Authority Prescription.	$60 / 30g	$72	No
Dietitian appointment	3 appointments	$200	$600	Yes

Treatment	Assumptions	Approximate cost (before Medicare rebate if applicable)	Approximate cost per annum (before Medicare rebate if applicable)	Medicare Rebate Applicable
Psychologist appointment – food allergy anxiety	5 appointments	$200	$1000	Yes
Allergist appointment - private	One visit per annum, including skin prick testing.	$500	$500	Yes
Dermatologist appointment - private	First visit 350 then 2x $280 for follow ups.	$350	$910	Yes
Wet wrap garments, Tubifast® and bandages		$250	$250	No
Dust mite proof bedding (e.g. Allergend™)	Single bed mattress cover, doona cover and pillow cover.	$350	$350 (one off)	No
Antihistamines (eg Zyrtec®)	Zyretc® is over the counter. One tablet per day	Zyrtec® 70 tabs $30	$156	No
TOTAL (before Medicare rebate if applicable)			**$7190**	

Child 2 - allergic rhinitis and severe, difficult to control asthma

Treatment	Assumptions	Approximate cost (before Medicare rebate if applicable)	Approximate cost per annum (before Medicare rebate if applicable)	Medicare Rebate Applicable
GP visits		$80 x 5	$400	Yes
Respiratory Physician visit – private	3 visits	$350 plus $280 per follow up visit	$910	Yes
Allergist visit - private	One visit per annum	$300	$300	Yes

Treatment	**Assumptions**	**Approximate cost (before Medicare rebate if applicable)**	**Approximate cost per annum (before Medicare rebate if applicable)**	**Medicare Rebate Applicable**
Asthma preventer (e.g. Flixotide® *)	Available on prescription	$42	$258	No
Asthma reliever (e.g. Ventolin® *)	Available over the counter or on prescription.	$8	$96	No
Nasal steroid preventer (e.g. Dymista® = $50)	Available on prescription	$50 for 120 doses	$300	No
Antihistamine (eg Zyrtec®)	Zyretc® is over the counter. One tablet per day	$30 for 70 Zyrtec® tabs	$156	No
Dust mite proof bedding (e.g. Allergend™)		$350	$350 (one off)	No
TOTAL (before Medicare rebate if applicable)			**$2770**	

*****This medication is available on PBS but some medication is restricted to severe cases or particular allergic disease states

This estimate does not include:

- Electricity to run dryer to dry all clothes and bed linen out away from pollen.
- Electricity to run hot water bed linen washes
- Electricity to run air conditioning and decrease humidity in summer months
- Time off work to care for children with allergies – specialist and GP visits, time off school
- Time taken to do wet dressings for eczema – up to 2 hours per day during whole body eczema flares
- Time taken to cook for children with food allergy
- Time taken for meetings with school staff, and for the parental supervision required for special food days at school
- Tissues during hay fever season
- HEPA filter vacuum cleaners
- Leather furniture and hard flooring

Annexure D

Non IgE mediated food allergy

Over the last 15 year period more and more individuals are being diagnosed with food allergy that is severe but does not lead to anaphylaxis risk. These debilitating immune mediated allergic reactions to foods are not immunoglobulin E **(IgE)** mediated and present differently, they are referred to as non-IgE mediated food allergy.[19]There is much less understanding around non IgE mediated food allergy, including but not limited to conditions such as Eosinophilic Oesophagitis (**EoE**) and Food Protein Induced Enterocolitis Syndrome (**FPIES**). These conditions are often debilitating and greatly impact quality of life. Treatments for non IgE mediated food allergy vary. Parents are often disillusioned and frustrated by the lack of communication between specialists, and specialists and the GP, with the parent often chasing reports so all health professionals can be informed of current results and treatments.

The financial and quality of life costs of these conditions can be immense. Individuals diagnosed with non IgE mediated food allergy often are required to see multiple medical specialists, have regular diagnostic procedures, purchase specialised formulas and foods for feeding (PBS subsidised for children, but not adults), have interrupted schooling and employment, and require medications that are not PBS listed for their condition (but are for other conditions).

Atopic dermatitis (eczema)

Atopic dermatitis (**AD**), often referred to as eczema, has increased in prevalence in Australia. This allergic disease state cannot be cured. Every day management of AD is essential and for some, even with care, the disease is debilitating and isolating. Inconsistent and incorrect information makes the task of keeping on top of a treatment regimen even more difficult.

People managing severe AD often lose hope they will ever get better. Some cannot work or attend school because despite optimal treatment, their ability to work and attend school is severely impacted. These people have often been put on medications known to have significant adverse effects with long term use. Once people stop using these prescribed medications as advised by their specialist, the severe AD returns, leaving them no option but to return to treatments and the cycle begins again. People with AD often feel there is no way out. A&AA health educators have spoken with adults who are depressed and despondent and have given up hope that life will ever change for them. Some people with severe AD stop seeing specialists as they have become despondent and are therefore not aware of new treatments on the horizon.

Some people are so desperate they seek help through alternate therapies. Many are put on elimination diets risking the possible development of food allergy when re introducing the food. Without proven success, many are put on very restrictive diets that can further impact quality of life and have no long term benefits.

People with severe AD desperately need access to treatments that are registered and used with great success overseas. The possibility of the game changing drug, Dupilumab®, has becomes a life-line for a small number of Australians with severe AD who access it on compassionate grounds. Having the PBS listing rejected for a second time impacts the mental health as well as physical health of those with AD even further. The impact of rejection of a potentially life changing medication cannot be underestimated.

Insect allergy

Allergic reactions to insect stings are common in Australia. While most trigger mild to moderate allergic reactions, anaphylaxis is not uncommon. Insect stings such as that of bees, wasps, ants including fire ant, green ant and Jack jumper/hopper ant, march flies and others can trigger anaphylaxis.[20]

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[19] For more information about non IgE mediated food allergy see https://www.allergy.org.au/patients/food-other-adverse-reactions.

[20] For more information, see https://www.allergy.org.au/patients/fast-facts/insect-and-tick-allergy.

Immunotherapy programs for insect allergy are effective, greatly reduce risk of a severe allergic reaction and improve quality of life of those able to access them. Insect immunotherapy also decreases the burden on the healthcare system, as people are less likely to need emergency treatment for anaphylaxis. Many are unaware that immunotherapy is an option for them.

Tick bite and the risk of developing mammalian meat/product allergy is an issue that needs greater attention. Education on proper tick removal to prevent mammalian meat/product allergy development is required.

Deaths from insect allergy, like food and drug allergy have increased in Australia. People that have insect sting anaphylaxis should be referred to an allergist for information on management, emergency treatment including recognition of anaphylaxis and adrenaline autoinjector administration, and possible immunotherapy.

Allergic Rhinitis

Approximately 18% of Australians live with allergic rhinitis (hay fever). Many seek over the counter medications when treating their symptoms and simply accept their condition without seeking medical diagnosis and advice. There is a huge need for community awareness around proper diagnosis, treatment and possible immunotherapy for those with moderate to severe allergic rhinitis.

Whilst some people have their allergic rhinitis managed by their general practitioner, others are referred to allergists without treatment for allergic rhinitis being commenced by the GP. This inappropriate referral leads to even longer wait lists. Those with moderate to severe allergic rhinitis should be referred to an allergist for further investigation and possible immunotherapy. Immunotherapy for inhalant allergens is not covered by the PBS and therefore many cannot access it despite research showing effectiveness.

Those with poorly managed allergic rhinitis are at greater risk of developing allergic asthma and thunderstorm asthma so it is critical people access appropriate diagnosis and treatments in a timely manner. Allergic rhinitis, a chronic allergic disease, can be seen as a trivial allergic disease, however it is one that can greatly affect quality of life as it impacts sleep, concentration, self-esteem and self-confidence due to ever-present symptoms.