Allergy and Immunology CAG
Response to Green Paper
Executive Summary

- Tasmania is the only state or territory in Australia that does not have an integrated and coordinated Allergy and Immunology service.
- Health services typically grow organically over time responding and reacting to the population’s needs. Scattered across Tasmania there are a range of Allergy and Immunology Services, but these are disconnected and piecemeal.
- Hospital admissions for anaphylaxis (severe life threatening allergic reaction) have increased 4 fold in the last 20 years. Food-induced anaphylaxis has doubled in the last 10 years.
- Allergic disorders should be considered alongside all other chronic conditions and acknowledged for the burden on quality life and demand on health services, their likelihood to be progressive and have significant co-morbidities.
- In 2007, the financial cost of allergies in Australia was $7.8 billion.
- The population of Tasmania provides the volume needed to sustain a local service.
- The absence of a coordinated service in Tasmania has meant there is no community of practice in allergy and immunity, lost opportunities in shared knowledge, adherence to best practice guidelines, and opportunities for collaborative research on how to best reduce the burden of allergic diseases.
- The lack of an integrated service contributes to a waste of resources, complicates access to services, and confuses patients and families about best practice care of allergic disorders.
- Modernising and coordinating Allergy and Immunology services in Tasmania is a low cost, high impact initiative which supports the principles of the Tasmanian Clinical Services Profile.

Introduction

The Allergy and Immunology CAG is pleased to provide this response to the Government’s Green Paper.

The CAG is supportive of the Government’s reform efforts to develop a Tasmanian Clinical Services Profile and acknowledges the important principles that will help guide the planning and delivery of clinical services in Tasmania.

Allergy and Immunological diseases (immunodeficiency and autoimmune diseases) are amongst the fastest growing chronic conditions in Australia. Hospital admissions for anaphylaxis (severe life threatening allergic reaction) have increased 4 fold in the last 20 years, and food-induced anaphylaxis has doubled in the last 10 years.1

Tasmania is the only state or territory in Australia that does not have a coordinated Allergy and Immunology Service.

There is a lack of public and medical awareness in Tasmania about the impact and appropriate management of allergic and immune diseases. Coordinating, modernising and redesigning the provision of allergy and immunology services in Tasmania would result in significant benefits for patients and the community, and provide the State with improved patient outcomes at an efficient cost.

Allergies in Australia

Prevalence

Allergies have emerged as a major public health problem in developed countries during the twentieth century; Australia and New Zealand have among the highest prevalence of allergic disorders in the developed world. It was estimated that in 2007:

- 4.1 million Australians (19.6% of the population) have at least one allergy;
- the highest prevalence of allergies is in the working age population; and
- there were 7.2 million cases of allergy (ie, an average of 1.74 comorbid allergies per person diagnosed with allergy).

If current trends continue, there will be a 70% increase in the number of Australians with allergy by 2050, with more than one in four Australians expected to suffer from an allergic condition, compared to one in five Australians today.

There is limited data concerning the prevalence of allergic conditions in Tasmania. However, we do know that the prevalence of most common allergic problems is as much as, or greater than, mainland Australia.

The prevalence of allergic rhinitis in Tasmania is around the national average of 15%2. Eczema and food allergy is more prevalent in Tasmania than in other states of Australia,3 and this is also the case with some autoimmune diseases.4

Costs associated with Allergic disorders

In 2007, the financial cost of allergies in Australia was $7.8 billion.5 Of this:

- $5.6 billion (72%) was lost productivity due to:
  - lower productivity while at work – ‘presenteeism’ ($4.2 billion)
  - lower employment rates ($1.1 billion);
  - absenteeism and lost household productivity ($196 million); and
  - premature death, including employers’ search and hiring costs ($84 million).
- $1.2 billion (15%) was the direct health system expenditure.

To put this in perspective, the cost of allergic disease is more than twice that of schizophrenia ($1.8 billion) and bipolar affective disorder ($1.6 billion) combined. Additionally, the net value of the lost wellbeing (disability and premature death) was a further $21.6 billion. This represents almost double the impact of either arthritis or hearing loss (both $11.7 billion).

In per capita terms, this amounts to a financial cost of around $1,912 per person with allergies per annum. Including the value of lost wellbeing, the cost is $7,200 per person per annum.

In Tasmania allergic and immune disorders are sub-optimally treated, with significant and growing costs to the individual and the community. Delayed diagnosis, and absent or prevalence’, Environmental Health Perspectives, Volume 111(4), (April 2003), pages 518-23.

inappropriate treatment increases morbidity and healthcare expenditure and may lead to permanent complications such as chronic damage to lungs and other organs or life threatening acute allergic events.

Current availability of Allergy and Immunology Services in Tasmania

Health services often develop in an organic manner to meet the health needs of individual populations. A number of high quality allergy and immunology services are currently being delivered in Tasmania. Each service has evolved independent of others. The formation of one Tasmanian Health Service (THS) is the ideal time to begin integrating these services to provide high quality, coordinated care for all Tasmanians.

Current services for Allergic and Immune disorders in Tasmania include:

- Jack Jumper Ant Program: insect venom immunotherapy, central clinic in Hobart, outreach clinic at the NWRH.
- Paediatric Specialist allergy clinics at the RHH and at the NWRH.
- Allergy clinics in primary care in Hobart and Launceston.
- Anaesthetic allergy service in Hobart (RHH) servicing all of Tasmania.
- THO Dietitians and hospital based clinics accepting Specialist referrals for dietary counselling on food allergy and autoimmune conditions, but not integrated with an allergy team.
- Antibiotic allergy service at the RHH but no service for rest of state.
- Autoimmune diseases – mostly managed by Rheumatologists. No public Rheumatology service in northern Tasmania.
- Immunodeficiency diseases – some paediatric coverage by general paediatricians. No Adult immunodeficiency coverage in public. Only one private immunologist in Hobart. Cover often provided by paediatric and adult Physicians who have not had specialist training in immunodeficiency diseases.

Service gaps

Gaps in the provision of Allergy and Immunology Services in Tasmania can be summarised as:

- Lack of coordination of services;
- Lack of expertise in allergy and immune care; lack of specialist allergist immunologist
- Lack of infrastructure; clinics, nursing experience; and
- Lack of an educational network.

Coordination

The lack of coordination of services can be demonstrated by a simple example that was discovered in the process of forming the Allergy and Immunology CAG. Two members of the CAG (a paediatrician and rheumatologist) became aware that they were both providing an allergy clinic at the NWRH. Each clinic serves a different patient demographic, however combining their resources and clinic times would lead to a degree of synergy around logistics and resources, and cost effectiveness. The clinics could be co-located and nursing staff shared. The presence of a Physician at both clinics would allow all patients to be billed under Medicare. Currently only one clinic can do this, resulting in lost revenue to the health system.
Case study: Paediatric food allergy

Sean is a 2 year old boy who lives with parents and 2 older atopic siblings on the East Coast Tasmania. He suffered from ‘reflux’ since birth and then began developing episodes of vomiting, irritability and rashes around his mouth after eating certain meals from the age of 5 months.

His parents were advised by his family GP to “just avoid cow’s milk” and this helped to some extent. His mother brought him to an alternative practitioner in Hobart for advice and a Vega Test (a clinically disproved test) showed allergies to wheat, dairy eggs, fish and peanuts. All of these foods were removed from Sean’s diet and after 3 months Sean stopped gaining weight, although the vomiting and rashes had become less frequent.

Sean was then seen by a second GP who specialised in alternative medicine and an extensive battery of IgG blood tests were performed through an interstate lab. The previously diagnosed food allergies were confirmed and five other foods including soy, sesame, potato and chicken were recommended to be removed from his diet.

His mother was becoming very concerned and confused about what to feed Sean so rang a specialist doctors’ consulting rooms for advice. They suggested a referral to the Royal Children’s Hospital (RCH) in Melbourne. After a 6 month wait Sean was seen in the allergy clinic and after skin prick tests and endoscopy was diagnosed with eosinophilic oesophagitis.

Sean had follow up appointments with the RCH clinic over a one year period. This resulted in most of the restrictions ceasing, and he began gaining weight. The visits to Melbourne, however, were burdensome for the family despite being initially funded by PTAS. The RCH recommended follow up by the Paediatric Allergy Clinic at the Royal Hobart Hospital and the family were relieved to find an effective local solution to following up Sean’s allergy problem.

Optimal Treatment Model

Rarely can an allergic or immune disorder be cured, so regular monitoring, review, support, and education become the cornerstone of successful treatment.

An example of a chronic disease treatment model that has been highly successful is that of diabetes. Diabetes is best managed holistically with care coordinated across the whole health spectrum: educated primary care; coordinated services between primary, regional, secondary and tertiary care; and the introduction of specialist nursing staff (such as Nurse Practitioners) and allied health to educate patients, schools and community organisations about self-care.

Treatment for allergic and immune disorders should follow a model much the same as that for diabetes. Allergic and immune disorders are essentially chronic conditions, and therefore are best managed by educating patients and their caregivers about how to best manage their disease.

The data suggests that Allergic and Immune disorders are, and will continue to be, a large burden on the Tasmanian health care system. If we fail to properly manage Allergic or Immune disorders in the community setting we increase the likelihood of acute presentations to the hospital system.

Coordinating the care for these disorders will lead to cost efficiencies and improved patient outcomes.
Benefits of an Allergy and Immunology Service for Tasmania

**Improving patient journeys**

Many patients with atopy (the combination of asthma, eczema and allergic rhinitis) can have an unnecessarily complicated medical journey as they are currently being referred to multiple specialists for treatment of their allergic symptoms and associated conditions. A central allergy service with general expertise in allergic disease would mean that the patients could be under the care of one specialist who gives consistent advice and support. This would help to decrease anxiety (a common issue for allergy sufferers) and improve quality of life.

Currently, the medical journey of a patient with an allergic or immune disorder in Tasmania is influenced by where they live in the state, who they see and the clinicians’ experience with and understanding of allergic and immune disorders.

**Coordinated care**

An integrated service would put the patient at the centre, improving their pathway to the most appropriate and cost effective care.

Primary care is often the first point of contact for the patient. We should aim to support primary care management first and foremost, then offer structured care pathways allowing equity of access at a state-wide level. Patients must be able to access the same level of high quality service, regardless of where they live.

**Expanding service delivery**

One of the specific needs in allergy care is the ability to safely undertake allergen challenges, including food and medication challenges. This is where a patient is given a suspected allergen in a controlled environment. The practitioner must have the resources to manage acute anaphylaxis if the patient has an allergic response. As such, the clinic must be located close to resuscitative care (for example, in a hospital).

Currently there are several primary care practises that subspecialise in allergic disorders. A great limitation to their service is their inability to access a clinic where the patients can undergo an allergen challenge. Those awaiting food challenges avoid the food until they are admitted for a food challenge. Long waits for this service mean that children could be:

- Avoiding food unnecessarily and this may affect growth and development; and/or
- At risk of developing further allergies because there is some research to indicate that unnecessary avoidance of a particular food could increase the risk of developing an allergy to that food.

Currently in Tasmania there are limited services able to conduct food and medication challenges and many patients are sent interstate for assessment and care, or are sent home with instructions on how to introduce a food they are ‘probably’ but not ‘definitely’ not allergic to.

Interstate treatment extracts a significant cost on the Patient Travel Assistance Scheme as well as the extra time taken to fly interstate with the additional time away from work or education.
In recent years several paediatric allergy clinics have been established and this has improved the care in this area. However the clinicians practising in these areas are isolated and again lack the synergy of resource and skill sharing.

**Better management of antibiotic allergy**

Studies have shown patients who are admitted to hospital and are thought to be penicillin allergic have increased morbidity and mortality, increased cost and length of stay by 0.6 days.6

Research has shown that 10% of the population claims to have a Penicillin allergy, however only 10% of these people have a demonstrable one.

Access to appropriate assessment and testing is vital to avoid patients being unnecessarily denied treatment with an appropriate drug. The inability to accurately diagnose drug allergy may result in the need to use more expensive or inappropriate medications subsequently increasing morbidity and healthcare expenditure.

The Infectious Diseases Unit at RHH offers a management program for diagnosis of drug allergy for inpatients; however, there is no statewide approach. Expanding this program to the entire state under the umbrella of a statewide Allergy and Immunology service will decrease morbidity and mortality, decrease cost and decrease length of stay.

**Better management of anaesthetic allergy**

The frequency of anaphylaxis during anaesthesia in Australia is approximately 1 in 10 000 which equates to around 10-12 cases each year in Tasmania. However, the number of patients with suspected anaphylaxis is higher. Anaphylaxis is a serious life threatening event carrying a mortality rate of approximately 3-5%, and significant morbidity of approximately 2%.7

After one of these episodes it is vital the patient has further immunological testing to not only investigate the cause, but to also determine which anaesthesia drugs can be used safely in the future to prevent repeat occurrences.

Currently an informal statewide service is provided through the Royal Hobart Hospital Anaesthetic Service. A formalised statewide referral centre based in Hobart for anaesthetic allergy patients would offer a number of advantages:

• The opportunity to manage these patients in Tasmania utilising skills, which largely already exist, thus providing anaesthetists around the state with a clear referral path to have these patients investigated.

• Concentrating the testing in one centre to ensure consistency and standards by maximising volumes of practice in one location.

• Basing the service in Hobart has the potential for a much closer working relationship with other immunological specialists. Often there is a need for allergist review in complex clinical cases. This coordinated collaboration in Hobart is currently lacking.

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6 Amrol D.J., ‘Penicillin Allergy Is Associated with Longer Hospital Stays and Increased Antibiotic Use’, reviewing Macy E. and Contreras R.J., *Journal of Allergy and Clinical Immunology*, (March 2014).

Enabling access and maintaining service volumes

With no public specialist Allergy and Immunology service in Tasmania patients often go without treatment, however some are sent interstate for specialised care. This comes at significant cost in terms of time and money for the state and the individual and their family. It is also worth noting that while other states do have their own Allergy and Immunology services, they are not meeting demand for allergy care in their own locality, meaning that Tasmanian patients are often placed on waiting lists to access care interstate.

In addition, the lack of a Tasmanian service impacts on the patient’s quality of life and trust in health practitioners, as patients may not always be able to access the information they require to manage their allergy. In an effort to cure or manage their symptoms, many patients with allergic disease turn to alternative therapies, however this approach can be fraught with danger.

There is a sufficient volume of patients in Tasmania to sustain an allergy and immunology service. The Northern Territory (population 240,000 people) has an Allergy and Immunology service attended by two FRACP-trained Allergists/Immunologists. The cost of funding a service in Tasmania could be defrayed in many different ways, for example by reduced PTAS costs.

Case Study – Accessing interstate care

Mastocytosis is a condition caused by the presence of too many mast cells.

In 2006, John (then aged 58 years) was identified to have raised mast cells and suspected mastocytosis. John was referred to The Royal Melbourne Hospital (RMH) for assessment by the Immunologist and Clinical Immunology and Allergy team. Over a period of several years, John and his wife Jane have been required to make overnight trips to Melbourne every four to six weeks to attend appointments at the RMH Immunology and Allergy clinic.

For John and Jane, this constant interstate travel to see the Immunologist in Melbourne has been financially draining, as well as having adverse effects on their physical and mental wellbeing, impacting on their quality of life. John has found the travel tiring and stressful and frequently requires a week of rest to recover from a trip.

John’s care has been further complicated by difficulties he has faced in accessing appropriate medical review following worsening of symptoms or anaphylaxis, and accessing prescribed medications from Tasmanian pharmacies. At times John has not been able to access the medication he requires which has negatively affecting his health, with a worsening of symptoms.
Better management of immune deficiency and immunological disorders

All immune system defects have multi-system impacts requiring regular specialist review, timely assessment and intervention to minimise complications. Treatment options include antibiotics, immunomodulation, immunoglobulin replacement therapy and in some cases bone marrow transplant. There is currently no immunology service in Tasmania to diagnose or manage these conditions and patients must travel interstate for assessment and care. This has a significant impact on the individual, the family and the community not only in terms of travel costs but also time away from family, compromised social supports and lost productivity/absenteeism.

Primary Immunodeficiency

Patients with primary immune deficiency require transfusions of immunoglobulins (the antibodies that defend the body from infection) derived from donated blood.

The National Blood Authority recommends that these patients be under the care of an Immunologist.8

The majority of Tasmanian primary immunodeficiency patients continue to receive these transfusions intravenously on acute day wards, despite a nationwide move for these patients to be educated and supported in the delivery of the self-delivery of their treatment at home.

Data on this demographic in Tasmania in not clear as these patients are currently managed by a range of physicians, including: haematologists, respiratory physicians and paediatricians, however each physician may only see a small number of patients with each different immunological disorders.

A coordinated allergy and immunology service, supported by an Immunologist would assist these patients in moving to the home care model, freeing up acute day beds and reducing admissions to hospitals.

Aligning with best practice models nationally and internationally

Every state in Australia, except Tasmania, has a coordinated allergy and immunology service. This is consistent with emerging best practice models for service delivery in this medical discipline in the UK.9

The coordination and integration of health services for any chronic health condition is likely to improve the delivery of services to where a patient needs them and be more cost effective.10

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**Improved education and awareness**

Because of the lack of a focal point for allergy and immunology management in the state there has been no structured approach to educating the general and medical communities. The establishment of a coordinated service would not only treat patients, but also educate the community about the risks associated with allergic and immunological diseases and appropriate management of these conditions.

It is also important to note that immune and allergic disorders interact with many other disciplines because the disorders are usually multi-system. There are a number of different specialties (including general practice) that would be enhanced by interaction with a coordinated Allergy and Immunology Service.

**Reducing Emergency Department presentations**

Presentations to Emergency Departments for anaphylaxis have increased by 400% in the last 20 years. Some of these presentations are for an individual’s first anaphylactic reaction but many are not. Optimal management with a heavy emphasis on education can reduce these secondary presentations. Hence freeing up the Emergency Departments to work efficiently and effectively.

As well as anaphylaxis there are many presentations to Emergency Departments for allergic reactions. These allergic reactions although not as dramatic as anaphylaxis clog emergency departments and can similarly be managed in an ambulatory setting.

**Access to telehealth services**

Management of patients with allergic and immunological disorders would benefit from better utilisation of telehealth consultations.

For example, patients requiring a specialist review could be assessed at their local hospital outpatients. Telehealth would support this with only the most complex travelling to a central hub.

**Improved telehealth facilities / access would allow more patients to be treated locally at their first contact with the medical system.**

**Improvement in mental health and management of secondary anxiety**

Although acute events may be sporadic for allergy sufferers, the fear and anxiety that accompany these disorders is ever present. For example, children who cannot go to birthday parties due to fear of food allergy or the farmer who cannot work without fearing an insect sting, anaphylactic reaction and potential death.

This psychological burden is hard to measure across the community but is large. For example we know 3% of the Tasmania population has an allergic reaction to Jack Jumper ants. Some studies have looked at the impact on quality of life from anaphylaxis and it is significant. The flipside though is that proper management has been shown to significantly reduce the risk of anaphylaxis and the fear that it generates.

A good example of an efficient service is the Tasmanian Jack Jumper Ant Program. In the ten years prior to its establishment four people died from anaphylaxis to Jack Jumper Ant stings. Since the program’s establishment
in 2001 there have been no documented deaths for Jack Jumper ant sting anaphylaxis.

**The Jack Jumper Program is a good example of Government support for innovative health care services that have had real benefits for patients and the community.**

It is not uncommon for a patient who is being seen in the Jack Jumper Ant Program to have held an unnecessary fear of a fatal anaphylactic reaction from their next sting. A percentage of these patients have a minimal risk of death and the simple act of clear information to educate them is all the management they require. They leave a thirty minute appointment that has significantly changed their life.

This very expensive process may well have been avoided if the cheese allergy could have been investigated during admission.

**Social and community costs**

Anaphylaxis can change a person’s and their family’s life in a moment. People can die from anaphylaxis and this leaves a large burden on their family and friends. However some patients have prolonged low blood pressure with an anaphylactic reaction. This can cause widespread brain damage leaving the person needing care for the rest of their life. These people are often young and otherwise healthy and they live for many years extracting a large financial and emotional cost on the community.

**Avoidance of unnecessary health service costs**

Many people claim to have allergies without ever having had these properly investigated and diagnosed. When a person declares an allergy, even when there is no evidence of diagnosis, the health service is required to take a precautionary approach. This can result in unnecessary health service costs such as provision of specially prepared meals to hospital patients.

In 2009, a hospital patient claimed to be allergic to cheese, while other forms of dairy foods were tolerated. When they were inadvertently presented with a meal containing cheese, even though no adverse reaction was recorded, it sparked an 18 month process of complaint, mediation, Ombudsman intervention, negotiation and settlement.
Recommendations

The Allergy and Immunology CAG strongly recommends that a coordinated allergy and immunology service be established in Tasmania to provide a tiered level of access to best practice of care from primary to tertiary care.

This would strengthen the safety and efficiency of clinical services through a coordinated approach to patient care as well as bringing efficiencies to an individual’s treatment and as a whole to the state by:

• Coordinating services with clear pathways for care;
• Integrating services to maximise resources and avoid waste;
• Educating the general and medical community;
• Ensuring that optimal care is delivered at each point in the healthcare system; and
• Enabling clinicians to work with other health professionals statewide to deliver the same quality of care to all Tasmanians regardless of where they live.

This would modernise care in Tasmania to the contemporary level offered in the rest of Australia.

Future Directions

The relatively short time frame for the preparation of this report has allowed the identification of keys elements of the argument for a coordinated allergy and immunology service.

There has been insufficient time to carry out an in depth analysis of the current services available, their existing resources and clinical load, and the deficits in service provision. As such it is hard for this report to make any specific recommendations about the nature of any such future service in Tasmania.

There is an identified clinical need for improved allergy and immunology services in Tasmania. However, what is required now is the will and drive to mould the backbone of current services across the state into a coordinated efficient system that will benefit all Tasmanians and ultimately reduce health care costs and ensure equitable access to care.

With the State Government’s in-principle support for the establishment of a statewide Allergy and Immunology Service, the Allergy and Immunology CAG would be happy to help facilitate this process further.
References


Amrol D.J., ‘Penicillin Allergy Is Associated with Longer Hospital Stays and Increased Antibiotic Use’, reviewing Macy E. and Contreras R.J., *Journal of Allergy and Clinical Immunology*, (March 2014).


**Additional resources**


