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MEMBERS IN ATTENDANCE: Mr Zimmerman.

Terms of Reference for the Inquiry:

To inquire into and report on:

Inquiry into allergies and anaphylaxis

The House of Representatives Standing Committee on Health, Aged Care and Sport will inquire into and report on:

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

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);

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

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

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

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

7. The impact of unnecessary drug avoidance due to unconfirmed drug allergies and its management, such as drug allergy 'de-labelling'.
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Committee met at 09:01

CHAIR (Mr Zimmerman): I declare open this public hearing of the health standing committee's inquiry into allergies and anaphylaxis. This hearing will be broadcast on the parliament's website and the proof and official transcripts of the proceedings will be published on the parliament's website. Thank you very much for participating this morning. I suspect this is probably the first time you've appeared before a parliamentary committee. We're not that scary! We hope that's not too daunting for you. I do need to go through a couple of formalities before we get underway, and this does sound very formal. I advise you that the hearing is a legal proceeding of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of parliament. The evidence given today is going to be recorded by Hansard, which means that it's on the public record and you'll be able to see a transcript of what you say, and it does attract parliamentary privilege—not that we're encouraging you to defame anyone! Thank you all for your written submissions, which have been very helpful. I invite you to make brief opening statements, then we'll move on to questions and a discussion. Fiona, are you happy to be lucky first? Who's had their coffee? That should be the leading question.

Ms Cheminant: Certainly. Good morning. I appreciate the invitation and the opportunity to speak with you all today. My daughter had her first ever anaphylactic reaction at 14, whilst at school. Her throat felt weird and became very itchy and irritated and her tongue began tingling, a sensation she had never, ever felt before. She became very distressed and headed to the student services offices. She explained her symptoms, but, as there was nothing on her record to state she had anaphylaxis and there was no allergy or anaphylaxis plan in place, she was told it could not possibly be an anaphylactic reaction. She did not receive any antihistamines, nor was she offered an EpiPen. An ambulance was not called and I also was not notified that the incident had occurred. Instead, my daughter was told to drink water and to return to class. Following this incident, my daughter was taunted by other students. She was accused of faking the reaction, being a fussy eater and also being attention-seeking. In home economics she was asked to cut up her allergen for a cooking lesson, and on a school retreat she and another student, also with reportable anaphylaxis, were shocked to be served their allergens for meals.

There needs to be better education for those working in schools, the health sector, both public and private, and in the medical profession. Being ill enough to be hospitalised, unable to eat anything off the daily meal plans provided, despite this information being provided upon admission and in writing on each individual menu, is totally unacceptable. Additionally, Australia's food labelling is woefully inadequate. There are many myths, lots of confusion and very little understanding about anaphylaxis and allergies. Dare I say it, there is also a significant lack of empathy amongst the community too, and I strongly believe the Australian media have had an enormous part to play in this area. My daughter is currently studying paramedicine. She knows she will be graduating next year with a deeper knowledge and understanding for her future patients. Thank you.

Mrs Duvbavica: My experience of becoming a first-time parent has been altered severely by the fact that my son has multiple food allergies. My son was born in 2016. I had a smooth pregnancy and a natural birth. I was able to be discharged within four hours but elected to stay overnight. As a newborn my son experienced severe reflux. He would often cry, arch and vomit and constantly had diarrhoea. I would lay him in his bassinet, only to find him and the bassinet covered in vomit. I breastfed on demand past the age of two. My son started fighting breast milk early, and I would have to trick him into breastfeeding by giving him a dummy then taking out so he'd latch on and breastfeed. I sought support through GPs and parenting hotlines, only to be told it was normal. Following advice, I would hand-express before feeding him, then burp him for 15 minutes. I would cycle his legs after every feed to relieve his abdominal discomfort. He woke every 15 to 45 minutes all night, every night. One GP encouraged me to leave him to cry, because she believed it was okay to show tough love.

By three months my son developed eczema. I was asked to apply thick cream six times a day and use a towel as a barrier in the pram, suggesting my son was allergic to the material. I felt accused of drying his skin out and questioned as to why I wasn't using formula. My son met all the milestones either ahead of or on time and continues to be above the 80th percentile. By four months and with much persistence on my part I was given a referral to see a paediatrician. By this time my son's eczema was infected and it required antibiotic ointment, his first antibiotics. The GP found my son to have abnormal bilirubin levels and referred us, saying, 'I don't want to be held liable.' He asked that we not mention the allergies, reflux and eczema, because he would manage them. The same GP sent us to the emergency department, because he feared my son had costochondritis as the cause of his arching. The ED discharged us, saying that my son was healthy, but encouraged us to see a dermatologist.
At four months we saw the paediatrician. Blood tests revealed allergies to cow's milk, protein, peanuts, soy, wheat and egg. I was encouraged to stop eating these foods. By five months, with no improvement, I sought an allergist and dermatologist referral. Again I met resistance. At six months the dermatologist suggested our son was reacting to the steroid-and-moisturising cream prescribed. We waited six months to see the allergist. We had been in ED during this time, yet were encouraged to wait for our private appointment. The allergist revealed our son was now at risk of anaphylaxis. He suggested that, in following the advice to cease all allergens in my diet, I had potentially caused lifelong allergies. He said, because we hadn't managed the eczema promptly, this was the cause of the allergies. When I mentioned the delay in seeing him, he replied that he had been busy.

The first 18 months in particular were horrible. We saw many specialists and even had a brief stay at Torrens House. It costs us financially, physically and psychologically. Despite the obstacles I would take my son out as much as possible. My son reacts to dairy residue in the air, so much so that his allergist advised us against child care. Even at the age of three we rarely eat out. It goes without saying that our son is not the only one that has been affected by this. As a breastfeeding mother I am. When he was 11 months whole old I was told that I am now at risk of osteoporosis later in life. I am disheartened by the medical system in particular, but also play cafes, restaurants, friends, families and members of the public. I believe that with better support for medical system we would not be sharing our story with you today. My family's life is forever affected by the path we have been down, and I'm sad to say that, despite trying my best, I was not able to help him find a better outcome.

Mrs Argenio: I'm Alex, but most the time I just get called Mum by our very special 4½-year-old daughter Evie. Evie has atypical food protein-induced enterocolitis syndrome, or FPIES. FPIES is a relatively uncommon non-IgE allergy. FPIES is an adverse food reaction involving the immune system. Currently there is no testing available for diagnosis, and avoidance of the suspected trigger food is the only recommended form of management. Thanks to our allergy informed paediatrician, Evie was diagnosed at around six months of age, at which point we were put under the care of a privately funded allergy team. At 10 months, due to her very early, very traumatic food interactions, Evie completely refused food that wasn't formula. Now, despite years of intensive feeding therapy. Evie is still sustained mostly by infant formula and the small number of foods that she feels confident enough to eat, as she cannot meet her nutritional needs with food alone. Evie's food anxiety remains complex and something that continues to affect us daily. While awareness around food allergy grows, non-IgE allergies seem to remain relatively unheard of.

I have two brief comments which I believe should be considered. Firstly, the psychological impact for children who experience early food-related trauma is significant yet still widely unacknowledged. As a result, there is little support available, nor are therapies such as feeding therapy readily accessible. Although different, the same lack of emotional support applies to parents. Seeing your child grey, cold and lifeless becomes carved into your memory. We live in a constant state of fear, wondering if and when Evie may become sick again and how significant of an impact it will have on her eating, moving forward.

Secondly, the financial burden of allergies can be monumental. At present, as privately funded patients, we have spent in excess of $20,000 on feeding therapy, at a cost of $195 per session, access to allergy specialists, medical professional consultations and infant formula. The level of intervention that is required for Evie to continue to make progress is not accessible for us within the public system. I simply hate to think of where Evie would be, had we not had the opportunity to access fortnightly individualised therapy for the past three-and-a-half years. You can't change our past experiences for us and you can't take away Evie's food allergies and anxieties, nor can you tell us with confidence that one day Evie won't be too scared to taste her birthday cake, but you can make a difference with your discussions today and during this inquiry, and I won't ever be able to thank you enough for that, so thank you.

CHAIR: Thanks, all of you, for appearing this morning. I know it can be tough and a little bit formal with this type of structure, but you've all done very well to sound like Mr Grace from Are you being Served?—for those who are old enough to remember that! Fiona, did your daughter's experience at school get better over time?

Ms Cheminant: Once we had a diagnosis and an EpiPen and she actually had full allergy testing we were able to avoid the foods that were triggering the reactions, but the problem is that, with a lot of foods, the labelling is just inadequate. I bought a lemon, lime and bitters drink, and I checked the labelling before I purchased it, as I did—and, no doubt, the other mums here do—with everything. She had one mouthful of that drink and she came to me and said, 'There's pineapple in it; I've reacted to it.' There was no mention of pineapple or any other fruits on the labelling. When I rang the company to verify what was in it, they refused to tell me and they cited 'intellectual property'. I know that other mums here have, no doubt, had similar experiences.

CHAIR: Food labelling is an issue that we've heard a lot about. I'm pretty sure that's going to be the subject of some of our recommendations.
Ms Cheminant: I hope so.

CHAIR: With the food labelling, one option that has been put to us is having a QR code or something like that, so you could just scan it with your phone and get the full list of ingredients. Would that make it easier?

Ms Cheminant: That would certainly help.

CHAIR: Alex and Sarah, how are your children progressing now? Are you feeling like you've got the right management regime in place now?

Mrs Dubravica: I think, for my son, we've certainly progressed, and we've done most of it ourselves, because we've been limited in what services have been available when we needed them, so I think, as a family, we've struggled to get to the point where we are today, but we have made progress. My son was initially very fearful of lots of people, because of all the tests from the early days. As such he's still very fearful of people he doesn't know, because he was undergoing tests from a very young age, but I think that we have made progress. In regard to his allergies he still has quite severe reactions to them, but we have faith for our future, I suppose. We still don't eat out. When I do go out and ask people about what's in their meals and things, I do get some attitude or dismissal from some people that are serving, because they don't understand completely.

CHAIR: Alex, do you think it was just luck that you saw a paediatrician that was able to identify so quickly?

Mrs Argenio: Yes, absolutely. We were very fortunate to have the paediatrician that we had from birth, who was very allergy aware and was able to, during just a rather casual conversation of, 'My child is vomiting to the point that she is saturating everything every time she eats or drinks,' from that little, flippant comment, work out that perhaps there was something else going on. There's no diagnostic testing, so, at this stage, it's just assumed by elimination that it is FPIES. We don't know the extent of her triggers. Last week, for example, she was sick for 10 days. I've got no idea why. I don't know what caused it. So it's ongoing, and that just reinforces those food fears. I guess we come from a different place. It's still relatively unknown, but she's doing incredibly well.

CHAIR: Dr Freelander? Our resident paediatrician. We have two on the committee; one's not here.

Dr FREELANDER: We can be quite ecumenical about that. Thanks for coming. I know that your families have all been through quite a traumatic time, trying to get to a diagnosis and have your child offered treatment that helps. I'm interested in the journey you had to diagnosis. Are your children being seen in a public hospital clinic or are they being seen privately?

Ms Cheminant: My daughter is now 21, but when she was diagnosed we went to a private allergist for diagnosis.

Ms Cheminant: I went to see our GP just hours after she'd had the reaction, and he just referred her straightaway to a private allergist. We were never presented with seeing anyone else publicly.

Dr FREELANDER: Was that because you couldn't get any satisfaction?

Ms Cheminant: That's privately, yes.
Dr ALLEN: You do have me, thank you very much, Chair.

CHAIR: Great.

Dr FREELANDER: Alex?

Mrs Argenio: Evie has been managed privately from day one. We saw our paediatrician privately and, because of the speed of the process and wanting to identify what was going on, we were put in touch with an allergy team privately, and our therapy is accessed privately.

Dr FREELANDER: Has she ever had an endoscopy?

Mrs Argenio: No. That's on the agenda, potentially.

Dr FREELANDER: Do the three of you think it would be simpler if you had a one-stop shop that dealt with this sort of problem?

Mrs Argenio: Absolutely. Each time we go to someone else. Our team is incredible, but the reliance is on me to filter the information and relay it. I'm not a doctor. I do the very best I can, but I guarantee you those people would prefer to receive information from one another, rather than me trying to translate it. So, yes, I think it would probably be more beneficial.

Dr FREELANDER: Do you get any financial assistance to deal with these issues? Do any of you get the carer allowance or anything like that?

Mrs Argenio: No. We get a healthcare plan now through our GP. I think it covers a few hundred dollars annually.

Mrs Dubravica: I applied for the carer payment and I was declined, but my son received the health care card.

Ms Cheminant: No, not for me.

Dr FREELANDER: Nothing, okay. Thanks very much.

Dr MARTIN: Thank you very much for sharing your experiences with us. I'm a psychologist and I'm interested in the psychological impact that this has had both on you as parents and on the children involved. I just want to know if you've engaged in any sort of psychological therapy, perhaps as a result of experiencing the anxiety associated with walking on eggshells—quite literally, constantly worrying about your child's health.

Ms Cheminant: Yes, my daughter has suffered from anxiety since this incident. She really felt the lack of empathy from the school the hardest. She really felt that they should have at least contacted me, and they didn't. In the school she goes to the use of mobile phones is not permitted by students, so she actually had to sneak into the toilets to call me. That's how I found out about the incident. Of course, a number of hours had passed since she'd had this allergen, and so it was too late to do anything. She suffered for 10 days with hoarseness and stomach pain and discomfort. It was just awful. Now she is fearful any time she can't identify what is in a food.

Dr MARTIN: Has she engaged in any psychological therapy?

Ms Cheminant: Yes, she has.

Dr MARTIN: How many sessions has she received? Have you found it useful? Has she found it useful?

Ms Cheminant: She has found it useful. I think she's had around 12 sessions.

Dr MARTIN: So her anxiety has reduced as a result?

Ms Cheminant: Yes, it has.

Dr MARTIN: What about you?

Mrs Dubravica: My husband and I are both seeing a specialist. My husband sees someone fortnightly, and I've only seen them on maybe six occasions. Only recently it was suggested by our GP that my son, who is three years old, should see someone as well.

Dr MARTIN: Are you able to claim any of those sessions?

Mrs Dubravica: I believe that there is the option to have a mental health care plan, but I know that has implications for our future and potentially for my child's future in certain jobs and in different areas that he may be interested in, so I have declined to do that, so it's an expense to us. I strongly believe and I know from what I have been through, through my personal experiences because I have been the primary carer through all of this, that if it wasn't for the career that I have I would have struggled even more so than I did.

Mrs Argenio: Little Evie has very significant food related anxiety. Often she has to be removed from her early learning during their lunchtimes, because it's incredibly distressing for her. She's not consciously making those decisions; it's very unconscious stuff. We control her world by removing food as a priority in our lives, so
we don't eat out and we don't put her in situations where she's going to become overwhelmed by that. So, yes. Is she anxious? Absolutely. Does she know it? I don't think so. We do live with anxiety. I have a diagnosis of PTSD from seeing Evie so unwell, so I privately manage that as well, but, yes, moving forward it has been raised that Evie may need a little bit of help, but we will see how she goes.

Dr MARTIN: Do you think it would be helpful to have more information about how to manage anxiety associated with a condition like a specific type of allergy?

Mrs Argenio: I think so. I spend a lot of time on Google trying to work out if my feeling is normal or if Evie's response to this is normal, and then bothering our allergy team with questions that are probably out of their depth, so, yes, I think so.

Mrs Dubravica: I think it's multilayered, especially if it's a very young child as you're already getting no sleep. I think that with no sleep—is it because they're not sleeping or is it because of the allergies?—it's very difficult. No sleep leaves you very vulnerable, plus this on top of it: it's a very difficult thing.

Dr MARTIN: Do you think that schools could better manage that initial reaction?

CHAIR: Thank you all for coming here today and sharing your very personal stories. The area of my interest is in education and also food labelling. I'm looking at outcomes from your perspectives. Firstly, Fiona, how do you think that schools could better manage that initial reaction? You said that there was no record of any prior reaction at the school. Firstly, do you think the school has records of other children who do have allergies and, secondly, how do you think the school could have had the tools to better manage that initial reaction?

Ms Cheminant: I really struggle to answer this question. We obviously have to provide allergy information at the start of the year to the school. One of Emma's friends has had nut anaphylaxis since childhood and her mother obviously provided that information to the school each year on their medical forms. They went on a school camp—this was just after Emma had been diagnosed and also had received her EpiPen. On this school camp they were served their allergens. Out came peanut butter for breakfast; out came fruit salad with pineapple and kiwifruit as well. They only had cereal and then they only had hamburgers for lunch. There was satay and that kind of thing. If you alert a school and you also provide that information on a camping form, you'd think that that information would be followed up, but, unfortunately, it's not. I really don't know the best way to answer it. In home economics, she was asked to cut up pineapple and kiwi fruit, and they are the two things that trigger her anaphylaxis.

Ms BELL: It's highlighted to me a lack of process around allergens within the school sector.

Ms Cheminant: Absolutely. Thank you.

Ms BELL: There are obviously very many other sectors as well, like food service, for example, where there are no warnings or there is no process around serving food to people with food allergies.

Ms Cheminant: Yes. But, even when she was admitted to a private hospital, on the menu plan it was fruit and nut cereal, muesli and milk for breakfast, or bread and butter. She wasn't able to eat the lunch menu either—it was loaded with cheese and dairy. We even wrote that information on the forms. We alerted the staff to it. After three days, we gave up. I just brought in food from home for her.

Ms BELL: So there some processes missing in there, particularly.

Ms Cheminant: Absolutely.

CHAIR: Was your daughter at a government or non-government school?

Ms Cheminant: She was at a Catholic school.

Ms BELL: Alex and Sarah, my question to you would be about what sorts of things you would like to see on food labelling. We have highlighted that there is a gap when it comes to food service—so when kids are at camp or when you're at a restaurant—and we have seen some sad instances of that around the country during this inquiry, where sadly people have had anaphylaxis, not so much in a school setting but in a restaurant setting. When you go out, it's very difficult for you. What sorts of things would you like to see when you're out and about with restaurants—warning signs or places that you can actually take your children to eat when you're not at school or at home?

Mrs Dubravica: Even the thought of school and kindy terrifies me, because I'm letting someone else take over control of this allergen, and some people don't have the same level of understanding. In our everyday environment, because we don't go to those places currently—we go to play cafes quite often—I don't know how I can manage it. Quite often people are there—parents drinking their coffees—and all it takes is the cow's milk residue in the air and my son gets a hoarse voice; it could be scratching on the inside of his throat. So I have to take him out of that environment. The difficult thing for me is that, when I present to those places—the play cafes...
or the restaurants—and have to bring my own son's food because they can't provide a meal for him, I am treated like a difficult patron, because you're not allowed to bring food in. But I'm not trying to save money—I wish my son could eat there. There was one occasion at an iconic South Australian place where we were forced to eat outside on a cold, wet day. Because my husband was eating at the restaurant—he had to eat outside—and my son had his own food, we weren't allowed to eat in the restaurant, and I think that's very disappointing. So, sorry, I'm not sure how you can manage that. I don't know.

Ms Bell: I think education is the key across all sectors as to the severity—and this is a very serious health concern—of how it affects people when they eat the incorrect foods.

Mrs Argenio: Food labelling for us isn't a big deal, because Evie won't eat it. She has a very controlled diet. So, although I understand it's a big deal, for us it's not a personal impact. The educational side—absolutely, and the process. We are very fortunate with our early learning. But essentially we're relying on people that don't have a big understanding of allergies to create a process to keep our children safe. All children are so diverse with their allergy needs. Our school have said it would be so much easier if they knew exactly what to do and how to manage these different things. They don't know what FPIES is; I can give them a crash course from my understanding, but how does that help? So, absolutely, in terms of processes, I think it would be very beneficial.

Chair: Dr Allen, do you have any questions?

Dr Allen: No. It is looking at the difference between—

Chair: Sorry, you are fading in and out; I'm not sure whether it's us or your speakerphone—

Ms Cheminant: I think there is a lot of confusion amongst the community with regard to what an allergy is, what an intolerance is and what anaphylaxis is.

Chair: Yes, I understand your point. Have you had any assistance or found useful support from allergy patient groups?

Ms Cheminant: Yes. Allergy and Anaphylaxis Australia have been fantastic. I think they have been a wonderful organisation.

Chair: If there are no other questions, I thank you again very much for coming this morning. Your evidence has been really useful, because obviously we hear, as we should, from a lot of medical experts, but really hearing your lived experience puts it all in context as to what we need to try and achieve. So, thank you very much for your time today. We'll send you a transcript of today's proceedings. If you find any errors in that, please get in contact with our secretariat staff. Or if there's any additional information that after today you think the committee could usefully receive, let us know. Thanks for your time.
GOLD, Professor Michael, Senior Consultant, Department of Allergy and Clinical Immunology, The Women's and Children's Hospital  

PALMER, Ms Sacha, Nurse Practitioner, Department of Allergy and Clinical Immunology, The Women's and Children's Hospital  

QUINN, Dr Patrick, Paediatric Allergist and Clinical Immunologist and Medical Unit Head, Department of Allergy and Clinical Immunology, The Women's and Children's Hospital  

[09:32]  

CHAIR: Welcome. Thank you very much for joining us this morning. I'll just go through the formalities, which you've probably heard already. I need to remind you that these are formal and legal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and in some circumstances might be regarded as contempt of parliament. Today's proceedings are being recorded by Hansard and attract parliamentary privilege. Thank you for making your time available and also for your written submission. Would one of you like to make an opening statement?  

Dr Quinn: We'd like to start by thanking the members of the committee for their interest in this important area and for the opportunity to speak to you today. I work principally in public practice in the Department of Allergy and Clinical Immunology at the Children's Hospital here in Adelaide, but I also work one day a week in private practice. Sacha Palmer, who is our allergy nurse practitioner, also works in the department. And Professor Mike Gold leads our clinical research—our translational research program—as well as providing clinical care and works through the University of Adelaide, through our department. The department provides quaternary care in allergy and clinical immunology to children from birth through to 18 years of age for South Australia. We provide care through training and research as well as clinical care, and we work across the entirety of the specialty. But the majority of our work is in the area of food allergy.  

The inquiry would have already heard about the rising prevalence of allergy and poor access to specialist allergy care and the significant burden this places on those with allergies in our community. South Australia's not different in this regard. We have more than 1,100 children on our public waiting list with median wait times of more than a year to be seen. And these are median wait times, so some of those children are waiting two or three years or more to see us. The long public waiting times disproportionately affect those most disadvantaged in our community and those with the most complex clinical needs.  

Long waits for definitive care are not simply a matter of inconvenience. There are risks of significant consequential harm, particularly in children, such as nutritional compromise; the development of long-term feeding disorders and the ongoing risk of severe allergic reaction, including anaphylaxis, because of a failure to properly identify the trigger allergens; and incomplete or active emergency management strategies such as the provision of an adrenaline autoinjector. We see multiple reasons for this access block. These of course include the rising prevalence and the fact that poor public resources have not really kept up with this.  

We also see the relatively poor level of knowledge around allergies in the healthcare workforce, particularly amongst generalists, which in turn leads to a high referral rate. While private care is available, this can be cost prohibitive for many and, because provocative food challenges do not attract an MBS payment, these important investigations are not available to those in private care.  

The solution is a multifocused one. There needs to be better resourcing of the public allergy services for clinical care, training and research. We would like to see expanded training in basic allergy care as part of university and postgraduate vocational education for medical, nursing and dietetic workers, particularly at the generalist level. Access to an appropriate MBS rebate would facilitate private care and decrease the burden on the public clinics. There is scope for expansion of the Commonwealth funded Specialist Training Program, the STP, not just for vocational paediatric allergists but also as a re-imagined program for the training of GPs, general paediatricians, nurse practitioners and other members of the healthcare workforce through public hospital allergy departments.  

The important work of the Australasian Society of Allergy and Clinical Immunology and the National Allergy Strategy should continue to be supported. Lastly, we would like to see further support into research into the primary prevention and treatment for food allergies—areas where we ourselves have made important contributions and continue to work. With that introduction, we'd be happy to take your questions.  

CHAIR: Thank you.
Dr MARTIN: I'm particularly interested in the research in understanding possible causes of allergies. Is there any research that is starting to help us understand the various causes of allergies, in particular, in maternal health? I'll leave it at that.

Prof. Gold: That question could probably do with a parliamentary inquiry in its own right. To keep it brief—

CHAIR: Give us a two-minute parliamentary inquiry response!

Prof. Gold: You have an expert resource on your panel with Katie Allen. She has been, and still is, an international leader in research in terms of allergy prevention and causation.

CHAIR: So was she any good?

Prof. Gold: The reasons are very, very complex and they do relate to many of the issues that we ascribe to a westernised or developed lifestyle. The individual factors are difficult to tease out, but they are multifactorial. I think the issues are that, as Patrick said, since the early nineties, we've described it as an epidemic. For someone who's been around since the early nineties, we've certainly seen that. It's going to be difficult to identify specific triggers, because it is going to multifactorial.

Dr MARTIN: Sure. Is there anything that's building in terms of the research that's holding promise or you're confident enough to put in place so that we can implement on a practical scale preparation for—

Prof. Gold: I think the paradigm shifts that have occurred during my working time in allergy relate to prevention of food allergies through allergen exposure early in the first 12 months of life and using that as a particular example. The next paradigm shift is really looking at potential ways of treating food allergies, particularly peanut allergy, in various ways. I think those are the major paradigm shifts that have occurred over the last few decades.

The translational aspects of that, particularly in regard to potentials for food treatment—that is, immunotherapy—are going to create a huge demand and a burden on the public system. The reason for that, really, is one of risk. These interventions, particularly in regard to potential treatments for food allergy, do carry a risk of anaphylaxis and will need to be hospital based. I think we're looking at a scenario that is only going to be exacerbated in terms of public demand and availability of public resources.

Dr MARTIN: On maternal health, is there anything that's building in terms of the research that could be utilised on the public?

Prof. Gold: I suppose the issues that interest allergists in terms of prevention would be maternal exposure to food allergens, and omega-3 fatty acids would be another intervention. I don't think there's going to be any magic bullet that's going to be able to turn off the epidemic. I only see it as a progression, for very complex reasons related to lifestyle and environment.

Dr MARTIN: So there wouldn't be any specific advice we could give the women who were of child bearing age that could assist with preventing the development of allergies at this point.

Prof. Gold: No. There's a lot of advice one could give, but, really, those are not going to be potent modifiers would be my guess.

CHAIR: Can I just clarify that. I thought the current advice, which has changed over the years, was quite clear advice for mothers both during pregnancy and during breastfeeding—for example, not to avoid allergens—

Prof. Gold: That is correct.

CHAIR: and vitamin D.

Dr MARTIN: Yes, that's what I thought.

Prof. Gold: All of those things would be advice that we would give, but I think in terms of modifying presentation it's not going to turn off the allergy switch. Of course we give that advice: don't restrict diet, vitamin D is important, a health diet is important et cetera.

Dr Quinn: The advice that we can give antenatally and the things that we can do to prevent that risk are quite limited, and there's still lots of exploration that we need to do about that. Things like vitamin D, modes of delivery and all these sorts of things may be important, but it is multifactorial. There is not going to be one thing that we could offer. That said, I think the biggest paradigm shift, as Mike has indicated, is this idea of avoidance early in life. In the very short time since I started—I'm not that old; I've got about 15 years of allergy experience as a specialist—there has been an enormous paradigm shift. I started recommending that children don't eat nuts until three. That was completely the wrong advice; it is well shown now by good quality research. So this idea of early exposure to drive tolerance is very, very important. That is something where there has been a lot of work done by societies such as ASCIA, the Australasian Society of Clinical Immunology and Allergy, to try and get that
message out there. It's been difficult for that to get out there go to end, but it is starting to get out there now that small children shouldn't avoid things. That actually feeds into one of the things that I'm very concerned about with our long waits in public clinics. We get children who see GPs, who might have a blood test. They may think they're allergic to something and they may or may not be allergic to that and they get foods withdrawn from their diet. As a consequence of that, if they then have to wait months or years to see us they run a significant risk of developing allergies they may not have had. Early quality advice both at a generalist level and at a specialist level is very important to intervening in the process, but there is an enormous amount of research that still needs to be done.

**Mr ZAPPIA:** Dr Quinn, in your opening remarks you said there's a waiting list of about 1,100 kids and that they are waiting for up to three years. Are those waiting lists increasing or have they stabilised?

**Dr Quinn:** Those waiting lists are increasing. Sacha actually triages our patients. Our waiting list is a cleaned waiting list. We go through it every few years and see who needs still to be on that waiting list. That waiting list grows, I think, by about 80 children a month at the moment. It's growing rapidly.

**Mr ZAPPIA:** It grows by about 80. How many would be treated? What would be the net growth per month?

**Dr Quinn:** How many do we see, do you mean?

**Mr ZAPPIA:** Yes.

**CHAIR:** So it's growing by 80 minus those you actually see.

**Mr ZAPPIA:** That's right.

**Dr Quinn:** One of the difficulties is that we don't have a cure for allergies, so there's an enormous case load that's been building over time. We're probably only getting through 50 or 60 new patients a month as the number grows, although we're seeing a lot more than that with our review patients that we see annually or every two years.

**Mr ZAPPIA:** I have two other questions. You referred to GP training, saying it would be helpful if they did more training when they did their medical training. Have you spoken to the AMA and the RACGP about that?

**Dr Quinn:** I personally haven't. I was previously a member of the ASCIA council many years ago, and I know that at that time—this is some years ago—there was an approach to the RACGP to include mandatory training for allergy as a portion of training in the paediatric training programs. The paediatricians have to do certain things as mandatory training, and what we have suggested is that maybe three months of mandatory training—say, in community medicine—could be checked out, if you like, to do three months of allergy training, not for the whole cohort but for a portion of the cohort. That was felt not to be appropriate by the RACGP.

**Mr ZAPPIA:** Lastly, I get the impression that there is a general perception out there in the community that children grow out of allergies as they get older, or at least some do. Is that correct? If so, what percentage would grow out of an allergy?

**Dr Quinn:** It depends on the allergy. The commonest allergies in small children are egg and milk, and in fact the majority of children grow out of those allergies—certainly by about five to seven, and many of them before that. For allergies such as nuts, the majority of children don't grow out of those, so 80 per cent of those would have those for life. The rates of allergy are much higher in small children, because a number grow out of them. But you've also heard today about other sorts of allergies—non-IgE allergies—and they're becoming much more common—things like FPIES, eosinophilic esophagitis and other sorts of things like that, which probably were always there but which we didn't recognise.

**Mr ZAPPIA:** Thank you.

**Ms BELL:** Is it not also true that anaphylaxis can strike at any time, at any age, without any previous allergy?

**Dr Quinn:** It's true that it can strike at any age. The dogma—and I think the dogma's probably true—is that you need a prior exposure in order to become allergic, if you like. But that exposure can be quite cryptic. That can be in utero. That can be through foods the mother has eaten, through the breast milk. Very commonly, it's through environmental exposures. If we were to vacuum your kitchen, we'd be able to detect wheat, egg, milk and other things in there. So children—particularly those with eczema, who've got broken skin and a barrier problem—will be exposed in that way. So it often seems like the first exposure, but there have been these cryptic exposures previously. We certainly see small infants, under one, who have anaphylaxis.

**Ms BELL:** Just moving on to patient record systems and record-keeping systems, my understanding of what that looks like now is limited. I'm wondering if you could outline to us what the record-keeping system is like and how it could possibly be improved, particularly in a school environment or a preschool environment—that sort of institutional environment.
Dr Quinn: Maybe Sacha could talk more to that, because she has a lot to do with the schools.

Ms Palmer: I was going to just start with the hospital system. All our medical records have alerts at the front of the notes, so any food allergies or drug allergies should be written there. As far as the schools are concerned, there is an anaphylaxis policy that was released in the last year by DECD, our department of education, which is easily accessible and available to all schools, so it's available to public schools. As part of that policy, they introduced what we call general-use EpiPens. All public schools, childcare centres and kindies now have EpiPens as part of their first-aid kit. As far as what individual schools do in terms of alerts, that varies. Most will have the child's action plan and picture up in the staff room, the front office or something like that.

Ms BELL: Clearly, that's not across the whole country; it's a school-by-school, state-by-state scenario—

Ms Palmer: Absolutely—yes.

Ms BELL: It appears that, by harmonising that across the country, it would significantly help.

Ms Palmer: National standards would certainly help.

Prof. Gold: I think the issues are around implementation and monitoring. That's what you need to fix. The policies etcetera are there, but you've had lived examples from the three parents that presented here. They've quite clearly given examples of implementation falling apart and also monitoring. To me, the parental histories were extremely important and really showed a failure of the system. That's really what is demonstrated in terms of the public health system, to me. We really have been burdened by the fact that the major specialties—cardiology, respiratory and gastroenterology—that those sorts of empires, were built within our public health system in the seventies and eighties. Allergy came along in the nineties. None of the resources have flowed towards that. The funding mechanisms that exist at a state level—and, granted, you'd be looking at the federal level—are just unable to address that problem. If you could focus the inquiry or try to focus the mind on how that could be solved at a state level, because it's the state that really delivers the public health system, that would be a significant contribution.

Dr FREELANDER: We've heard some patient histories that have been very disheartening. We've also, in the course of our inquiry, had lots of suggestions about what we could do to improve the system, many of which, it seems to me, are very likely to make the situation worse, not better, and may well be a significant cost burden to the health system without actually improving the system. In particular, getting an item number for food challenges is fraught with danger and the potential to be exploited, in the same way as some of the new treatments that are becoming available at enormous cost run the potential to drain the system of resources without changing the system. I have my own views about the situation. I certainly think that any public clinic that has a waiting list for over 12 months is not working. I believe in a multidisciplinary approach to food allergies across the spectrum. Can you tell me three things that you think would improve the public health system?

Prof. Gold: I agree with your comments completely. What we need is the basics. We don't have the basics in place. To think that various high-end monoclonals etcetera are the answer is just not correct. The first point is we have to make our hospitals and our CEOs accountable. If they have 1,000 on a waiting list, they have to be accountable to actually seeing those patients and dealing with them. There's no accountability in the system. I suppose the second point is to flow that through to resources. If there is accountability, they need to have the ability to find the resources in order to deal with those patients. The third point would be to have the public health system as a node for education and research. If you basically integrate research with clinical and teaching, that improves everything. It improves the research, it improves the clinical and it improves patient outcomes etcetera. You could do those three things. I agree with you about focusing on things like the challenge of the MBS. I think that's important but I agree with you—there is a risk of that in terms of exportation, lots of challenges outside of the hospital-setting risk. We have not had any deaths in Australia as far as I know from food challenges but if that were to happen, that would disadvantage the whole system.

Dr Quinn: I guess one of the greatest challenges we face is when a referral comes in and someone is asking for help. It is a piece of paper but there is a GP or a general paediatrician behind that who has run out of skills. Sometimes that is very appropriate what comes in and sometimes it is very clear they have no idea. Training our general health workforce—the GPs, the general paediatricians, the community dieticians, the child health nurses, the entire health workforce—in basic allergy care would take a lot of the workload away. It would reduce a lot of morbidity from people waiting unnecessary amounts of time and at least the people you got to see would have had some basic management before they turned up. We are at the point now where we will see a referral come in, we think the child is at risk of anaphylaxis so we send them a script for an EpiPen, because they cannot wait a year to see us. We have never seen this child but that is a risk-mitigation strategy.

Dr FREELANDER: So you will actually send a script for—
Dr Quinn: It is a risk-mitigation strategy. We don't want someone to come to great harm on our waiting list. Look, sometimes that is going to raise their anxiety. Often we hope we will reduce it but at least it keeps them safe. We take on clinical risk having never seen a patient, with a piece of paper. If there was a way to improve the quality of the information on that piece of paper, that would also be very helpful, and there are strategies one could think of that could do that. I won't list three; I will list that one—better education.

Dr FREELANDER: Presumably, Sacha, you're the one who has paediatricians beating on the end of the phone?

Ms Palmer: Yes, I triage about 140 referrals a month and I probably spend about six to eight hours a week dealing with referrals because we do have a fairly robust decline system. So when we decline a patient—about 20 per cent of our referrals per month are declined—I will actually explain why—we have a template letter—and try and give some feedback and some education around whatever the particular problem is. About probably five patients per month I will send an EpiPen to. I don't send a script but I send a letter to the GP asking the GP to do a prescription. The parent gets a copy as well and that has been a very successful strategy.

Dr FREELANDER: Are the majority of your referrals appropriate? No, that is a leading question.

Ms Palmer: No, they are not. We get a lot of referrals for very basic hayfever management—please see this child, who has hayfever—but they haven't started treatment.

Dr FREELANDER: So in other words, the workload could be reduced a lot if there was appropriate triage?

Ms Palmer: I guess there is a lot of my workload spent on dealing with referrals that we don't need to see.

Dr FREELANDER: Do you always contact the GP?

Ms Palmer: Yes.

Dr FREELANDER: So that in itself is form of education?

Ms Palmer: Absolutely, yes. I don't want to just send a referral back with no reason saying why we are declining. I also send them a copy of our referral guidelines as well.

Prof. Gold: Just to clarify: those thousand referrals have been triaged. Those are the ones that we triage that should be seen; that is a very important point. I think we have 17 pages of referral guidelines on the internet from our hospital. So 80 per cent are triaged as being appropriate and 20 per cent are not. But that is a very clean waiting list; those are triaged. According to our standards of health care, those patients should be seen and prioritised one, two and three.

Ms Palmer: And most of those are peanut or egg allergy, just not anaphylaxis. These are very deserving children.

Dr FREELANDER: So they need to be seen?

Ms Palmer: Yes.

CHAIR: I have asked this before but in every inquiry this committee has done since I have been a member of it, one of the most common themes is concern about the level of education that general practitioners have. Everyone comes and says, 'GPs need more training,' and I wonder what they are studying at university because nothing in our inquiries seem to get much of a look-in. I'm just wondering, how do you cope with the problem of GP overload and what is reasonable and not reasonable for us to expect of our general practitioners, who are general?

Dr Quinn: That's a good question, because GPs are experts in undifferentiated care, and I would struggle doing their job—they do a fantastic job—and there are many GPs out there we don't hear from. Presumably, they've got the skills they need to do the work they need to do. I think, if you look what's through the undergraduate education, there's very little undergraduate education analogy. Even just doing a few more lectures and a few more placements, like that, would make a difference. You don't have to educate every single GP; you just have to generally raise the level of knowledge in the community. By providing effective opportunities for them to engage with specialists and the public hospitals, be that formal courses or professional development placements within hospitals, those sorts of things—even just having that human contact with your allergist in the public hospital, so you can ring them up. We often ask, 'Please call us. Don't just send a referral. Call us and we can send you things to do while they're waiting.' We rarely get a phone call. We just like to be called.

Dr FREELANDER: What about your training scheme? Do you train many people in allergies?

Dr Quinn: Our department has recently had its accreditation reduced, in terms of our ability to train.

Dr FREELANDER: Is that right?
Dr Quinn: Yes. We don't have a fixed training registrar. Our registrar is the general paediatric registrar that comes out of the general pool of registrars, but occasionally they'll identify as wanting to train in immunology. We have been very successful in doing that over the last few years. We've managed to train four or five registrars, I think, in the last seven or eight years. We had our training reduced not because of the quality of training we deliver but because our registrar was so burdened with service work that the college didn't feel they could get enough training opportunities. So I think a little bit more junior staffing would actually help that.

Dr FREELANDER: So your accreditation was actually—

Dr Quinn: Yes. We were previously accredited for two years core training, and we've had that reduced to one year of core training, recently. The reason for that was not because of the amount of clinical work but because our registrar is off doing things, like writing discharge summaries, instead of seeing more patients in a clinic.

Dr FREELANDER: So the response to that could be to increase the number of registrars, would it?

Dr Quinn: The response may not be to increase the number of senior registrars; it may be to increase the number of interns or junior registrars, at the bottom end, to allow them some general training, and allow our vocational registrar, then, to be unburdened with some of this leg work and they can concentrate on more useful things for them.

Dr FREELANDER: A relatively simple situation.

Dr Quinn: Yes, and relatively inexpensive.

CHAIR: Do you have any questions, Dr Allen?

Dr ALLEN: No, thank you. I thank all three of you for participating in the inquiry this morning. It's been very useful for us. We'll provide you with a copy of the Hansard transcript and if you have any additions or corrections please let the secretariat know by the 28th of this month.
The term we use for those who are regarded as being penicillin allergic or regard themselves as being allergic to penicillin is that 'they carry a penicillin allergy label'—in other words, they are labelled with 'penicillin allergy' and this label may appear in their health records or in some cases on themselves as a form of a medic alert or even an allergy tattoo.

However, we know from many published studies that the majority of these people—greater than 90 per cent, and perhaps as much as 98 per cent—are not actually allergic to penicillin and could take it quite safely without reaction if they wanted to. So we have a huge number of erroneous penicillin allergy beliefs. The term we use for those who are regarded as being penicillin allergic or regard themselves as being allergic to penicillin is that 'they carry a penicillin allergy label'—in other words, they are labelled with 'penicillin allergy' and this label may appear in their health records or in some cases on themselves as a form of a medic alert or even an allergy tattoo.

As we know, the vast majority of these labels are inaccurate. Why is this a problem? When a patient carries a penicillin allergy label and they have an illness due to bacterial infection and they require an antibiotic, the patient can't be given penicillin, which is often the most effective and safest treatment for their infection. So they need to be treated with a non-penicillin antibiotic. Other antibiotics might be less effective, be more expensive and carry risks of side effects or other reactions. Many studies have shown that patients who bear a penicillin allergy label...
have a longer hospital stay, higher re-admission rates, and are given a broader range of antibiotics than are strictly necessary, and this has led to worse outcomes and in some populations even higher mortality rates.

The other problem of course with this is that this broader range of antibiotics that is necessary has the effect of increasing bacterial resistance in the community and thus may play a part in the generation of antibiotic resistant superbugs.

How do people acquire a false label of penicillin allergy? Well, often it's because of a minor reaction, such as a minor rash in childhood which might be caused by the virus rather than the antibiotic; or because a family member had an allergic reaction or because they had a side-effect which was not really an allergy, and there are many other reasons. So these labels tend to metastasise: what starts out as a minor rash with amoxicillin becomes, after a while, an allergy to all penicillins, which, later on—because people don't remember the initial event—gets called an anaphylaxis to penicillins, and that later forces avoidance not only of all penicillins but also of cephalosporins—which are a cousin to the penicillin family and also a quite useful family of antibiotics—because there's a theoretical cross-reaction rate. So if you see somebody who has a label of penicillin allergy and you don't know how bad the allergy was, you just tend to avoid all of those antibiotics, which puts the person at a disadvantage. This sort of metastasising of the allergy label occurs through a process of medical Chinese whispers, whereby one report gets converted into another report. It is also, it has to be said, due to careless and inadequate recordkeeping at the time of the original reaction.

What I've described is a situation in which effective and accurate drug-allergy labels are very important to prevent serious and dangerous and, indeed, potentially fatal reactions in those who have a true allergy. But inaccurate labels, which are very prevalent, can cause harm to the patient and the health system. So, what is to be done? There are both concrete projects which can be undertaken at national and state health system levels as well as an improvement in knowledge, by education of health practitioners—a recurring theme—and even the general public.

What we would like to be able to do is to remove false drug-allergy labels, or, as we call it, de-label patients wherever possible, and more broadly if possible. According to our population survey, there are, theoretically, 90,000 people in South Australia who would be eligible for what we call 'low-risk de-labelling'. Basically, that is the supervised administration of penicillin under medical observation. At present, de-labelling is only carried out by clinical immunology and allergy specialists in hospitals or specialist clinics with very limited capacity. We suggest that protocols should be developed—and this is an initiative potentially underway through ASCIA—which might enable other health practitioners to identify those who are at very low risk of actually being allergic and therefore to de-label them safely in another healthcare setting aside from a specialist allergy clinic. Furthermore, those who are at moderate risk but who still might require penicillin and who probably are not allergic, we'd like to be able to expand capacity for day-patient testing in hospital under our unit. This, I might add, would be—and I know this is a topic of some disagreement—facilitated by the development of an item number for allergy challenge in either Medicare or ABF schedules.

Secondly, we believe that patient safety and optimal management would be served by a single source of truth clinical record. Clearly, the My Health Record is in the ideal position to provide that sort of single source of truth. Currently My Health Record can include drug allergy information, but the structure and design is very poor. The National Allergy Strategy has been trying to work with the Australian Digital Health Authority to improve its functionality for allergy recording, but the area is currently under-resourced and we've not been able to achieve a significant change. The My Health Record is, of course, currently under-utilised at present, but it does make great sense to us that this should be the primary source of accurate and validated information, which is linked to other prescribing and health records throughout the community and health system. We've been looking at the development of a validated drug-allergy incident report which could be included in the My Health Record to retain a permanent record of the nature of the drug allergy reaction and a foundation for further investigation where appropriate.

Finally, we have mentioned education, and I do believe that broader education would help improve the accuracy of drug allergy reports. We know that 60 to 70 per cent of drug allergy reports in hospital electronic health records are entered by nurses with limited immunological and pharmacological training. We also know that GPs have limited knowledge on the significance and evaluation of drug allergies. Finally, I've mentioned My Health Record: it turns out that the primary mode for entering drug allergy information in My Health Record is that this is actually self-reported by the patient; again, with a potential for error.

To summarise, drug allergies can be dangerous, and drugs must be avoided where there is a serious risk. But there is also a great deal of unnecessary drug avoidance, which disadvantages the patient and the healthcare
system. We would like to be able to improve the effectiveness of drug-allergy warning systems in serious cases, as well as increase the accuracy of drug allergy labels and remove false labels where appropriate.

**CHAIR:** Thank you very much, Dr Smith. We will move to questions. Dr Allen, do you have any questions?

**Dr ALLEN:** Yes; thanks very much. It was a great presentation. There are a lot of drug allergies but not a lot of [inaudible] and we could end up having to [inaudible] for people who may never need that particular antibiotic. Do you have any sensible way to deal with that?

**Dr Smith:** I'm sorry; I didn't quite catch every word you said. I think what you might be referring to is prioritisation of the evaluation of these drug allergies. Is that correct?

**Dr ALLEN:** Correct.

**Dr Smith:** We do have a matrix for that. There are several parameters. We prioritise those who have several different drug allergies and for whom the choices are beginning to narrow, and those who are infection prone and who, either through having required more than one or two courses of antibiotics per year or having an immune deficiency or a pre-disposition such as asthma or chronic sinusitis, require antibiotics. You are right: there's not a high priority to investigate everybody in the population—and we certainly wouldn't suggest that—but, for those who have a high antibiotic requirement or potential requirement in the future, we'd like to be able to use the best available antibiotics and therefore not have to avoid necessarily the basic penicillins.

**Dr ALLEN:** Thank you. I think this is an incredibly important area and an area, from a health economic point of view, that costs billions to the Australian health sector.

**Ms BELL:** I have an interest in this, actually, because I am one of those adults who has successfully avoided penicillin since the age of seven, when it was administered and—my memory tell me—I had some kind of fit and ended up in hospital for a couple of weeks in a coma. I would love to be able to take penicillin in those situations where I would need to. What would be the risks for someone like me and the process for someone like me wanting to test to see if I am in fact allergic to penicillin or whether something else happened at the time? I have no way of checking what actually happened, apart from my parents' memory.

**Dr Smith:** That's a really good point, and you've given us an excellent case for consideration. Firstly, many of the patients who we see in our clinic who are avoiding penicillin are doing so for far more minor reasons than what you've outlined. Even if there were a rash in childhood—which often would not occur in any case in adulthood—there's a perception that allergies worsen and that what could have been a rash in childhood could turn into anaphylaxis in childhood. This is in fact a misperception in most cases.

Obviously what you've outlined is a rather alarming history, and we would like to get more detailed information. I would not expect your own GP to deal with what you've outlined; I'd expect your GP to refer you to me, because obviously, as I said, you've outlined something which is potentially very serious. Having said that, there are all sorts of reasons why that might not be an accurate recall or why there might have been other reasons for that hospitalisation.

Hospitalisation is actually one of the questions we ask to determine the seriousness of an allergic reaction. So, yes, that's something a doctor would take seriously. Having said that, there are various reasons why that not be a true penicillin allergy or why you might not be allergic anymore. Indeed, even if you had been seriously penicillin allergic as a child, except in the worst cases, the allergy can often be outgrown, in the same way as a milk or egg allergy can be outgrown by children as they grow up. The process that we would need to do is evaluate your history in great detail and find out whether there were any contemporaneous records available and perhaps even question your parents, if they were available for questioning.

**Ms BELL:** I was actually in this state at the time.

**Dr Smith:** It would be interesting to know if there is something that is available. Having gone through that process, we would then need to book you in as a day patient for assessment, and you would likely undergo a skin test with penicillin, which is an injection of a small amount of diluted penicillin under the skin. If that test were negative, you would then undergo what's called a penicillin challenge, by administration of greater doses of penicillin—so 100th of the dose initially; wait for an hour and then one 10th of the dose—looking to see if there were any signs of allergic reaction or anaphylaxis.

**Ms BELL:** So would it be half a day or—

**Dr Smith:** This is a day admission that's done at the Royal Adelaide Hospital.

**Ms BELL:** At what sort of cost would that be to the health system?

**Dr Smith:** I don't have costings through the health economists, but a day admission to our day unit—there's a difficult economic process there, because it's not funded adequately through our activity based funding models or
Determining whether you are allergic without having to expose you to the thing that you're suspected of being allergic to is where the blood and skin tests come in that we might have to use. Having said that, those blood and skin tests are also inaccurate and cumbersome so we go straight to an oral challenge in those who have a very low risk. If you think that you're allergic, but I think no and that you have a very low risk of genuinely being
allergic—and if you are of a very low risk of having a dangerous reaction—I'll just give you penicillin and watch you. That's the basis of the observed challenge. Having said that, most doctors are reluctant to do that—and with good reason. There are medical, legal and clinical concerns, and so it does take a certain degree of experience and knowledge to be able to make that decision.

Once the label has been verified, if you like—if we say, 'Look, you actually are highly likely to be allergic,' or the tests show that you probably still do bear the allergy; or maybe we expose you and you do have a reaction, but in a controlled environment, obviously, where we can manage that so it can be done safely—then the allergy label is verified but there is no central source of truth at the moment. We believe that the My Health Record is obviously the appropriate place for that central source of truth.

One of the other problems that I haven't mentioned—and perhaps I will just diverge slightly—is that if we prove you're not allergic to a substance then we call that 'delabelling'. Potentially, we can take 95 per cent of those people who think they're allergic and prove they're not actually allergic. The problem then becomes: (a) convincing them to take it in the future and convincing their health practitioners to give it to them in the future—even though we've proven it and we write a letter to say they're not allergic; and (b) the labelled group remains in other hospital records and other medical records. If they go back to hospital they might say, 'My doctor did tests which showed I'm not allergic.' But the hospital staff might say, 'But hang on, it says here that you're allergic so we're not going to give it to you anyway,' because there is a medical and legal risk involved.

So we actually have to thoroughly clear the label from all health and medical records. This becomes a very difficult process, which is why, again, the My Health Record might be a central source of truth, containing a record which says that this patient has been delabelled and therefore they are not considered allergic as of 2020.

Mr ZAPPIA: If an allergic reaction to a drug arises, though, do you have an obligation, say, to report it to the TGA or to the manufacturer of the drug?

Dr Smith: Theoretically, there is an obligation to report it as an adverse reaction. That doesn't happen a great deal currently because the primary purpose of the TGA adverse drug report is pharmacovigilance: in other words, they want to know if there are new or unexpected side effects that they ought to be wary of with a particular drug. Now, unless the drug has a particularly high allergy rate, allergies are an accepted adverse effect. That is not a big surprise to anybody, so they're not reported.

The other thing about the TGA reporting system is that it does not link to a patient name at all. It's a way of the TGA becoming aware if the drug has a safety signal or a problem associated with it that they need to be aware of. But it doesn't help the patient in the slightest as an individual.

Mr ZAPPIA: No, I realise that. But it might be an alert that GPs and the like, who are going to prescribe it, might be aware of.

Dr Smith: Yes, that's a fair point.

Dr FREELANDER: That was the question I was going to ask—

Dr Smith: Oh good, thank you!

Dr FREELANDER: in a slightly different way. I don't believe the present situation is adequate for notification of drug reactions. The classic example is the serum sickness reaction to cefaclor, which was quite common. We were seeing a lot, and yet there were very few notifications. I am just interested in your view on the present situation for notification of drug reactions.

Dr Smith: It is a good point. We tend not to push drug allergy notifications, and maybe we should. My concern is more with the individual and how they're going to manage their ongoing situation. I don't want to diverge too much, but in New Zealand the adverse-drug-reaction reporting system is actually linked to the patient health record. That provides the patient with the benefit, in the sense that that can then be traced through to prescriptions and through hospital admissions. We would advocate for that as a system. There is a motivation for drug allergy adverse-reaction reporting then.

The allergic reactions that occur from time to time—serious allergic reactions to medications—are not unknown to the medical system. So unless there were a new drug with a particularly high rate of adverse reactions, and where pharmacovigilance became an issue to report that, it's not a priority. But I do agree with you that it ought to be considered as a priority, and perhaps we ought to be encouraged to do a bit more.

Dr FREELANDER: Thanks very much.

Dr ALLEN: I have another question, with regard to workforce. Dr Smith, would it be fair to say that adult allergists are dealing more with drug allergies as a burden of health, so to speak, but that the referrals can sometimes be difficult because there is not enough workforce availability—not enough drug allergy clinics?
you mentioned, there is no Medicare item number for drug allergies. Do you think we would have a sufficient workforce if there were to be a Medicare item? Would you want it restricted to allergy-trained specialist doctors, or would it be appropriate to have much stricter criteria for the Medicare item to ensure that people weren't overusing the Medicare item inappropriately?

Dr Smith: Thanks, that's a good question. I presume there would need to be some sort of economic evaluation. I have already said that there are 90,000 people in South Australia, so that would perhaps create a pipeline for those who would like to make a commercial exercise out of it.

My opinion is that we actually have been increasing the allergy specialist workforce in South Australia recently. I'm not sure how that's going nationally. We've documented over a hundred delabellings. In fact, I've used them myself in my private practice clinic. So there is great scope to be able to do that in community clinics and in private practice specialist clinics. I think that could achieve a great deal. But then there are the higher risk patients who I believe need to be managed through hospital, and that's where our bottleneck is that moment.

Dr ALLEN: Thanks.

Dr MARTIN: You mentioned before that testing doesn't necessarily transfer to changes in behaviour. I think that would then need to be evaluated: how many people will change their behaviour and take penicillin, for example, if they've been delabelled, versus the cost of actually having an MBS item allocated to test it. We'd have to know that people would in fact change their behaviour as a consequence, otherwise—

Dr Smith: Sure. I think that item would need to be tied to a comprehensive package of label modification and central recording in the My Health Record, and with communication with all involved practitioners. Yes, that is a problem and, yes, it's not a good idea to introduce a clinical practice which is not going to have a clinical outcome. But the point is that if I were in that situation I would like to know that the patient could receive penicillin if they were in hospital with pneumonia, even if the GP wouldn't prescribe it for a sore throat.

Dr MARTIN: Exactly.

Dr Smith: I guess the point is that if there were factual records that the patient had been delabelled and they presented with meningitis, pneumonia or a serious bacterial infection then the hospital should recognise that and they should be given penicillin.

Dr MARTIN: But the issue is twofold: it's not just the labelling from the past and the accurate information once the labelling has been removed; it's actually the fear in the patient about taking the medication and following—

Dr Smith: Yes, which is why we do give them the medication orally as a course of medication. One would have hoped that the fact that they've actually taken it at home—the course includes three days of administration at home—does overcome that fear.

Dr MARTIN: Yes. Okay, thank you.

CHAIR: Thank you very much for your evidence this morning. You probably heard me say before that we'll provide you with a Hansard transcript of today's proceedings. If there are any additions or corrections you want to make to that you can do that through our secretariat by 28 February. We very much appreciate your evidence today. Thank you.

Proceedings suspended from 10:34 to 10:46
ALEXANDROU, Mr John, Private capacity
FORSYTH, Ms Elizabeth, Member, Adelaide Hills Jumping Jack/Hopper Ant Action Group
GUDDEN, Mrs Jennifer, Operations Manager, Jack Jumper Allergy Program, Royal Hobart Hospital, Tasmanian Health Service
HISSARIA, Dr Pravin, Immunology/allergy consultant/specialist, Clinical Immunology and Allergy Department, Royal Adelaide Hospital
LE, Dr Thanh-Thao (Adriana), Immunology/allergy consultant/specialist, Clinical Immunology and Allergy Department, Royal Adelaide Hospital

CHAIR: Welcome. Before we continue, do any of you have anything to add in relation to the capacity in which you appear here today?

Mr Alexandrou: I'm a patient and also a community pharmacist in the Adelaide Hills.

Dr Hissaria: I'm a clinical immunologist at Royal Adelaide Hospital and also a pathologist with SA Pathology.

Ms Forsyth: I'm part of the patient group and speak on behalf of the Adelaide Hills hopper ant action group.

Dr Le: I'm a clinical immunologist and allergist at Royal Adelaide Hospital and I do some private work as well.

Mrs Gudden: I'm not a clinician. I oversee the management of the operations of both manufacturing and clinical ops within the jack jumper unit.

CHAIR: Fantastic. I need to remind you that these are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and in some circumstances could be considered a contempt of the parliament. Today's proceedings are being recorded by Hansard and attract parliamentary privilege. I invite you to make an opening statement before we move to questions.

Ms Forsyth: I speak on behalf of the Adelaide Hills hopper ant action group. I understand it is a South Australian issue across several regions, including the south-east and the peninsulas in South Australia. We are a group that was formed from patients participating in treatment following a morning tea attended by over 200 people in the Adelaide Hills that was put on by the hospital. The core issues of the group have been the lack of awareness of the risk of the ant and the associated risk to community groups and individuals in the hills—for example, gardeners, walkers, sports groups, schools, firefighters, tourists et cetera. Certainly, as a resident of the hills for 20 years, I had not been informed of the risk of the ant until I had my own experience of it.

We understand that the allergy can grow with exposure—and the medical team will speak more on this—and that's obviously a concern for the community. While you might get bitten once, if you get bitten several times, or you encounter a nest, the experience can be quite different and it can be a cumulative one. We certainly acknowledge the limited access to treatment and the associated costs. The treatment is currently only delivered from the RAH—which, from a hills perspective, is a journey into the city—and is limited to people who are selected for treatment.

There is an issue of quality of life for those who experience the allergy. It carries with it fear and potentially restrictions in terms of how you live. I certainly garden with a lot of caution. I live on 10 acres and need to clear my land for fire prevention and other activities. I think that some people have a much more extreme experience.

We're also concerned with the education of the group. We believe that it's a hidden issue in the community. The community does not know widely of the issue until it happens, and people actually express quite a lot of surprise when you talk to them about it. We do also know that the ants are quite widely spread in the Hills. There's a lack of research, but we wonder if they're possibly increasing. Certainly, we encounter a lot of nests on our property. Whilst we're quite active in reducing them, we know that they also spread with but one survivor from a nest destruction. There is a lack of research on distribution and advice that we could be given on how to handle ants on our property. The group is seeking to develop a website and an associated campaign to inform the community, but we currently operate, like many community groups, with absolutely no resources. We understand that national parks do deliver and distribute some information on this.

The other issue for the group is the treatment availability. The RAH allergy team can speak more on this, but it is currently delivered through the RAH, as I said, with reducing accessibility to the Hills community. We're not sure about accessibility elsewhere in the state but assume that it is through the RAH—which is more serious if people need to travel that far. Personally, I waited three months to be seen by a specialist after my initial incident.
before being referred to the clinic and the trial. I wasn't prescribed an EpiPen during that period, which was of concern to the specialist when I saw him. I certainly think that GP education is needed in relation to that.

The other major issue as far as accessibility of treatment is concerned is cost. The trial has helped access for a number of participants because it has been free for the first year, but we understand that the treatment required is five years plus. I'm into year 3, and we have been benefiting since July this year from a subsidy provided by the hospital, but we believe that to be quite precarious because it is being provided by the allergy service and we know that there are pressures on the health budget. The cost that we were going to be charged for the vaccination was over $240 a month, so the cost could be in the region of $15,000 over five years if it wasn't subsidised. I'm a full-time working person, but I consider that a not insubstantial commitment to my health on top of other health costs.

I think the answer for people experiencing the allergy is to avoid treatment with the associated risks. We also understand there to be inequity for South Australians in that free treatment is available interstate, in Victoria and Tasmania. In summary, I think the risk to the community is the suddenness of the incident. You hit a nest without even realising it; because these ants are very mobile, they jump on your leg and they're biting you through cloth and your leather gloves, and you can experience multiple stings very quickly without even knowing that you've been exposed. Properties in the Hills can be quite isolated, so help can be some distance away and, indeed, that's a risk we take, but it certainly is highlighted by the nature of living in the Hills and the lack of education and awareness.

Dr Hissaria: Thank you for giving us the opportunity to present on this topic, which is actually very close to our hearts, for two reasons. First, the problem with sting allergies is that it's a very localised geographic-specific problem, so the answers to stinging insect allergies won't be found in research that is done in the US or Europe or elsewhere. All of these stinging insects are very much localised to a geographic location. What that means for us as doctors practising in this particular field in allergies is that we have to find answers to this. A lot of this work has already done by Professor Heddle. Most of the research that has been done was conducted out of Royal Adelaide Hospital by Professor Heddle. We have found out the extent of the problem and found an effective therapy, which is venom immunotherapy, and we have also tried to be smarter in the way we use it, by adding different adjuvants. That is the current clinical trial that we are doing—basically adding this adjuvant to the venom, which we source from Hobart—Jenny will speak on this later—so that we can use less of it, because it is a limited available resource.

The second thing about this problem is that it is very unpredictable—as opposed to a food allergy or a drug allergy, where once the label is there you know how to avoid it and you are less likely to accidentally ingest something, although it does happen—and, as Liz said, you can just be gardening and be stung after coming across a nest. So there has to be an effective therapy available, because it is definitely affecting quality of life in a very bad manner.

In terms of an effective therapy, we know that for venom immunotherapy the trials have already been done and it is highly effective. One year after a gradual build up, immunotherapy is basically a way of desensitisation against allergy. We know that in the clinical trial which was conducted by Professor Heddle that less than five per cent of people actually had an acute severe allergic reaction after having one year of immunotherapy as compared to 80 per cent who received a placebo, so it is a very highly effective therapy.

The first problem with its wide availability is inequity. Currently as comparison, honey bee venom is another stinging insect allergy that is very prevalent and is a world wide problem; hence, there are commercially available venom extracts which can be used for immunotherapy and they are subsidised by the PBS. So if you are honey bee venom allergic, you can be anywhere in Australia and anyone can prescribe it because it is PBS subsidised. In comparison for the jack jumper ant, because it is manufactured locally by the jack jumper ant program in Hobart—as I said, Jenny will be speaking about that—it is a limited resource and so is only available in certain hospitals—currently Royal Adelaide, Royal Hobart, Monash and another outreach clinic in Tasmania. These are the only four hospitals which offer this immunotherapy because it is a limited resource. There is no centre anywhere in New South Wales or ACT that offers this immunotherapy.

Second is the cost. The cost currently at least in Tasmania and Victoria is funded by the state government. In our hospital, it was never funded, so last year it was only after of this clinical trial that we could offer this therapy to the affected individuals. Lately, in the last six months, we have actually put in an application to the hospital and most likely the hospital pharmacy is going to fund it, but it is going to come out of the clinical immunology and allergy budget, which, as you can imagine, is very low, and this might take up the whole budget. We won't be able to treat any other immunological conditions even if we wanted to so it is going to be a significant strain on that.
The cost currently is about $3,500 for the first year during the build-up phase, where you use more venom because you give it more frequently. Thereafter it is about $2,500 per year for the next five years. It has already been said about the quality-of-life issues and the constant fear that people live in. There are about 300 subjects currently on our books. We did some maths and there are about 72,260 people who have been mapped living in that Adelaide Hills region. This is not even going to the south-east and Victor Harbour and so on, where there might be even more people affected by this condition. It is about 0.4 per cent prevalence in that particular geographic region. As Dr Le said, we currently offer it to the Royal Adelaide Hospital and not to the community, so it is a big problem, a problem for which we have an answer. We have a solution and it can be solved. I know that we keep asking for more resources for doing research and everything. Here the resources are to fix a problem for which there is an answer available.

Concluding, what we thought would be good to fix this problem would be that obviously, firstly, there has to be a nation wide funding model. Individual units cannot bear the cost of this medication because it is a big problem for us so there should be a jack jumper ant venom PBS subsidy or some form of federal funding should be made available. Secondly, as I said, it is a very local geographic problem, so we could actually have local clinics which are there, which would prevent people travelling distances to get this effective immunotherapy and a part of this could be simple things like setting up jack jumper ant speciality clinics in the Adelaide Hills with funding for allergy nurses and allergy specialists.

Lastly, we all talk about research and how much we like it. This might be a unique model because it is a very specific problem and there are lots of unknowns in the area stinging allergy in general about what dose to give in maintenance and how long to give it and what are the risk factors. I think if we use this model, because it is a unique and specific model, we might be able to answer a lot of those questions, if there was enough funding given for the research.

**Mrs Gudden:** Firstly, thank you for holding this inquiry and for providing us with an opportunity to discuss the complexities of allergy at a national level.

**CHAIR:** Have you come up from Hobart?

**Mrs Gudden:** I have come up from Hobart along with three of my colleagues from the hospital. Unlike our colleagues here today, we are in a different position. At the Royal Hobart Hospital, we are only funded for jack jumper ant venom immunotherapy. Tasmania is the only state without a coordinated public allergy immunology service. So although Tasmania is small in population in comparison to other states, the problems we face are the same. Allergic and immune disorders are sub optimally treated, with significant and growing costs to the individual and the community. Delayed diagnosis and absent or inappropriate treatment can result in poor patient outcomes. Without a public specialist allergy service, Tasmanian patients often go without treatment or are sent interstate for specialised care. This comes at significant costs in terms of time and money for the state, the individual and their family. Other states are burdened with local demand, which can result in Tasmanian patients being placed on waiting lists to access interstate care.

The Jack Jumper Allergy Program at the Royal Adelaide Hospital is a good example of what a small state can do with a bit of government support, but this success has not come easily to us. During the 14 years that I've worked with this team, we've fought very hard to keep the program funded. We've faced closure due to budget cuts on multiple occasions. But we refuse to give up, and that's because of our patients. We regularly hear how much they need help, so we persevere.

These people are generally active and motivated individuals who want to be well—they want to return to their work; they want to return to their gardening; they want to go bushwalking; they want to do the jobs that they do as a regular gig without facing the fear of being stung. To most people, this is an insignificant little insect, an ant, but to somebody with a severe allergy this ant connecting with their body can result in their death, and for some the risk is a very real. In the 10 years prior to the establishment of a Jack Jumper Allergy Program, there were four deaths in Hobart due to the anaphylaxis of a jack jumper ant sting, and there have been no recorded deaths since.

The psychological burden of allergy is hard to measure across the community, but it's large. Our staff take calls from people seeking help on a daily basis. The anxiety is evident when they're asked to record their worse sting reaction: ‘My throat felt tight, my tongue was swollen, my chest hurt and I collapsed. I thought I was going to die.’

The Royal Hobart Hospital is the only manufacturer of jack jumper ant venom extract internationally, and we supply our venom to Victoria and South Australia as well as to patients within Tasmania. After years of research we now have a proven treatment, and producing this venom is a labour-intensive process as it is manufactured under the strict guidelines of the TGA.
In collaboration with our colleagues at the Royal Adelaide Hospital, a trial is underway which may lead to a reduction in the dose and the amount of venom that we need to treat our patients. Unlike Tasmania and Victoria, South Australia doesn’t have budget allocation to support jack jumper ant venom immunotherapy treatment. This inequity is something that would like to see addressed. We would also like to see a reduction in waiting lists across all states and improved access to treatment through better resource allocation to clinical service delivery. Currently the average waiting time for patients to commence insect venom immunotherapy in Tasmania is well over a year, and I expect this is similar in other states.

I was recently asked why the scope of our business does not extend to other allergies. We have the foundation to build this service, but our core business is insect allergy. We want this to change also. Like other jurisdictions, we cannot expand our services without additional resources. In 2015 we welcomed our first allergist-immunologist to the Jack Jumper Allergy Program, and this allowed us to see Tasmanian patients with other allergic diseases. However, numbers are restricted. Patients with life-threatening allergy are seen as a priority, and others face extremely extended waiting periods.

We also commenced an antibiotic allergy clinic, as we are acutely aware of the immense burden inappropriate antibiotic allergy labels pose on individual patients and the health system as a whole. Delabelling of antibiotic allergy is a priority, but provision of this service is unfunded and therefore unsustainable for us.

Appropriately resourced and coordinated allergy immunology services give people the best chance of having their care provided in the right setting by the right provider, and fosters collaboration, education and integration with primary healthcare providers implementing a best practice model of care to improve the quality of life, reduce unplanned hospitalisations and achieve better patient outcomes for Australians.

CHAIR: Thank you very much. This obviously is a very unique problem to Australia and parts of Australia. In terms of people being diagnosed with a jumping jack allergy, in most cases is it through lived experience of being bitten by an ant? Can you actually get a pretest, or something like that, to test whether you’re allergic, and do many people do that?

Dr Hissaria: Yes, we have a blood test available, which we developed in SA Pathology. We are the only lab in Australia which does that test. We had that specifically made through our connections with Sweden with the Phadia people, so we have a blood test available which will test for specific IgE which tells you whether you have a propensity to having a reaction. It does not diagnose it but, in the context of a clinical history of anaphylaxis and if you have a positive blood test, it makes a diagnosis. If that is negative then you can do intradermal tests as well—which we offer in our clinic, and I guess Hobart does as well—to diagnose that allergy, especially if they didn’t see the ant or there were multiple ants in the mix.

CHAIR: Do you recommend people who live in particularly prone areas to be tested?

Dr Hissaria: The testing does not actually confirm the allergy. You need to have the clinical event. The problem with allergies is that there are two events. One is what we call ‘sensitisation’, whereby you have these antibodies which can make you likely to have a reaction if you’re exposed to it again. If you have a specific IgE, that’s not good enough. This knowledge comes from beekeepers. We know that 30 per cent of beekeepers can have positive specific IgE, but they might not be clinically allergic. So we wouldn’t recommend routine testing for it as a risk factor.

CHAIR: Mr Alexandrou and Ms Forsyth, how did you become aware of your allergy—through a nasty experience?

Mr Alexandrou: Yes, through anaphylaxis—I passed out, an ambulance came.

CHAIR: Did you know what had caused it straightaway?

Mr Alexandrou: Yes, indeed. I had been stung a few times beforehand, and I was aware that I was stung by a hopper ant.

Ms Forsyth: I was completely unaware. I just felt terrible. My daughter was there, fortunately, and she helped me out.

CHAIR: Did you know you had been bitten by an ant?

Ms Forsyth: I knew I’d been bitten, but I wasn’t in a state to comprehend what was going on.

CHAIR: Have both of you been through the venom immunotherapy successfully?

Mr Alexandrou: I have, yes.

Ms Forsyth: I’m still participating.
CHAIR: It's obviously a long process—a five-year process. Could you explain what it involves? Obviously, this affects access to the program, because if you're living in a more remote, regional area then potentially it's a huge burden, I would have thought, to participate.

Ms Forsyth: It's not an insignificant commitment. I'm currently going five times weekly. I was doing the four-week visits, and in the visit you have to stay in the clinic for an hour after the injection to ensure that you're not having any adverse reactions.

CHAIR: Over five years, what would a program look like?

Dr Hissaria: Initially, there is a build-up phase whereby you start with one-thousandth of a dose and then gradually build it up, which is done on a weekly basis for the first eight weeks. Thereafter you go fortnightly for a couple of injections and then you go once a month for three to five years. If you've done very well for the first two years sometimes we extend that four-week period to a five- or six-week period, but that is based upon the individual patient, how they tolerate the immunotherapy and whether they've had any further stings or not.

CHAIR: I don't think we've had any evidence on this. We had a particular focus in Sydney on tick allergies, which are quite different, I imagine. But, for other insect allergies, is the same treatment available, does it follow the same format, or is it unique for different species?

Dr Le: Dr Hissaria has mentioned that we have bee venom treatment available. That's quite an effective treatment. If you did not have bee venom immunotherapy and you had a history of bee venom anaphylaxis, it would bring your risk down from having a further anaphylactic episode on a future sting from around 50 per cent to 15 per cent. In comparison, jack jumper ant therapy has been shown in a very high-quality, randomised, placebo controlled trial published in The Lancet in 2003 to reduce the risk from 72 per cent in the placebo arm to five per cent. So it's actually more effective than bee venom immunotherapy, but bee venom immunotherapy is far more equitable to access.

Similarly, even with wasp allergies, which is the other immunotherapy which is PBS subsidised—it subsidises paper wasp and yellow jacket wasp immunotherapy—it brings the risk down from around 40 per cent to less than five per cent. We're talking about a greater reduction in anaphylaxis risk that is as effective as wasp venom immunotherapy but it's not accessible. We have far fewer wasp venom allergic patients, particularly in South Australia. In Tasmania, the jack jumper ant is the most common cause for anaphylaxis presentation in hospital. In South Australia the most common presentation in our venom allergy clinic is still around 60 per cent bee venom. That means one-third of presentations are for jack jumper ants and only a minority are for wasps. It's the dominate cause of anaphylaxis in South Australia and actually in other areas of Australia. The ant is very endemic in Tasmania but it's widespread in the Adelaide Hills. It's found on Kangaroo Island. It's found in the southern parts of the area like the York Peninsular. It's found throughout the ACT and NSW where treatment is not accessible. It can even be found in WA and Queensland. So it is a national issue.

CHAIR: Do you know what the instances of allergy is within the population?

Dr Le: The best data is Tasmanian. They have done a survey which showed a 2.7 per cent prevalence of immediate systemic allergy, which means the potential for anaphylaxis in their population. In semi-rural and rural Victoria that rate was 1.7, or nearly two, per cent. So this is not localised allergic reactions; this is generalised anaphylactic reactions. Unfortunately we don't have similar data in South Australia. That's something we would very much like to do—epidemiological studies. But in the Adelaide Hills I imagine it would be similar to the Victorian and Tasmanian data.

Dr Hissaria: A conservative estimate would be that we have 300 subjects on our book. This is a conservative estimate, so it will be higher than that. It's about 0.8 per cent. If you consider the Adelaide Hills region and the number of people that we have on our books with confirmed allergy that have been referred to us, it's at least 0.8 per cent but definitely higher than that.

CHAIR: Can you grow out of an insect allergy?

Dr Hissaria: The only way to find that out would be to do a challenge. No-one has done that. If you have anaphylaxis, you'd normally receive immunotherapy because that's the first line. But it is not a true what we call atopic condition, so, when we talk about growing out of allergies, it is specific IgE and some genetic disposition, like food allergy and asthma and everything. Sting allergy and drug allergy are not mediated by your disease, so they don't fall under what we call atopy. No-one knows the degree of outgrowth. If you want to extrapolate from drug allergy, we do know that in five years about 30 per cent of people with confirmed penicillin allergy can become tolerant or at least less allergic. I don't think there are any such studies available for insect sting allergies.

Dr Freelander: I'm interested that we don't seem to see a lot of people in my area with jack jumper ant anaphylaxis. There are ants there—
CHAIR: In Sydney?

Dr FREELANDER: Sydney, New South Wales, sort of Southern Highlands type area. I'm interested if you get people coming to your clinic from New South Wales for immunotherapy.

Dr Le: We have actually received a referral from New South Wales asking us to desensitise a patient. While we looked very seriously into it—to initiate their build up and then return them to their specialist or outpatient care in New South Wales for maintenance treatment—unfortunately it wasn't actually feasible. When we looked into it we were advised that the treatment is only licensed for our hospital to administer. They wouldn't be able to have the venom delivered to them in New South Wales to continue treatment.

A big thing is under-recognition, even in the Adelaide Hills where it's endemic. As you heard with John Alexandrou's story, he'd had multiple stings, and that's often the usual case with the stories—like Liz saying she had no idea about the allergy. Adelaide Hills residents have often moved to the area without knowing that the ants are there and that there's a potential for anaphylaxis. GP education is improving in the area but often the GPs don't know that there is a treatment available. We've heard of multiple cases of patients moving out of the vicinity. The other thing is that you don't react to the first sting. You need to be stung at least once to develop allergic antibiotics, so you will tolerate multiple stings.

The other thing is that there are 89 Myrmecia species, 88 of which are found in Australia and only one in New Caledonia, so it's a very Australian problem. There may be related ants that look like jack jumper ants that aren't similar enough to cause anaphylaxis. It would be interesting to know whether the ones you've seen in New South Wales are actually the same pilosula.

Dr FREELANDER: So your ants might be worse than my ants!

Dr Le: They might be worse—yes.

Dr FREELANDER: Who milks the ants?

Dr Le: Jenny.

Dr FREELANDER: How do you collect the venom?

Mrs Gudden: As I discussed in my opening statement, it is quite a labour-intensive process to actually get the end product. Myself, my colleague and many authorised volunteers with the hospital go into bushland areas within the state and we collect the ants in very small, handheld vacuums. Each nest is individually packed, put into a cooler and transported back to Hobart. Then they are frozen at minus 80 degrees. The next step of manufacture is that the individual venom sacs are dissected under a microscope by a laboratory technician. It's roughly 3,000 sacs per batch of venom to make the venom extract—the concentrate. It's the concentrated product that we send to Victoria and to Adelaide, and then they go through another manufacturing process there to make it clinical grade. But once we have all of our sacs ready, we go to the sterile-manufacturing suite within the pharmacy, where we're regulated by the TGA. Then the product goes through a filtration process. Then there are a number of extensive quality control checks that we go through before we release the product for human use.

Dr FREELANDER: So several ants are harmed in the process?

Mrs Gudden: A lot of patients are saved in the process.

CHAIR: The ants aren't volunteering their services in this.

Ms BELL: My question is around any other unscientific treatments that are available for jack jumper ant bites—perhaps where anaphylaxis doesn't occur, but a low-grade allergy is there. Is there anything available at all?

Dr Hissaria: Not that I'm aware of—nothing.

Dr Le: You can be stung and just have a localised allergic reaction. If you're stung on the finger, you might have swelling of the hand or arm. That generally doesn't predict a sufficiently high risk of having anaphylaxis with the next sting, so we don't generally advise venom immunotherapy for those patients—just local measures. But I have not heard of any alternative treatments. For patients who don't have venom immunotherapy, it's avoidance and an EpiPen, which is a very imperfect solution. They still have poor quality of life: they're very vigilant and anxious, and often an EpiPen may not be a sufficient quantity of adrenaline. In The Lancet trial that Professor Heddle conducted, when they had anaphylaxis in the placebo arm the average amount of adrenaline that those patients received was 700 micrograms, which is well above two EpiPens.

Mr ZAPPIA: Jenny, you said that there were four deaths from this. Was that just in Tasmania?

Mrs Gudden: Just in Tasmania.

Mr ZAPPIA: Over what period? Do you know?
Mrs Gudden: Ten years: the 10 years prior to the program commencing.

Mr ZAPPIA: In terms of the immunotherapy program, I think it was said that there is no funding other than what's been provided through the hospital, and that it could well run out. So Medicare doesn't provide any support whatsoever for it?

Dr Hissaria: In terms of incidence of deaths, it would be fair to say that there would be much underreporting of the deaths. There is at least one where we suspected it might have been the ant, because it was a young cyclist who was found and there were some sting marks. People working on the farm or something, they just die and the most common cause we all put it down to is sudden cardiac death in the absence of any confirmatory thing. So we do think there is underreporting of the deaths due to this problem, especially in the people living in that geographic area where you are likely to be exposed to it.

Dr MARTIN: I want to know if there are any people that are predisposed to or at higher risk of this—for example, people with previous anaphylactic history, or asthma, or eczema or something?

Dr Le: As Dr Hissaria said, these patients are not atopic, so having a history of asthma or food allergy—that sort of thing—is not of relevance. In insect allergy—and this is the same for bee venom and for our jack jumper ant cohort—the main risk factors are being older, male and having cardiovascular comorbidities. Those people are most at risk of allergy and anaphylactic death. And, because the mode of death is cardiovascular collapse, it's very easy to miss. Even if you have a 100 per cent pretest probability of anaphylactic death, an autopsy will miss the diagnosis 50 per cent of the time, so we're definitely missing cases. When they've studied anaphylactic deaths in Australia, frequently the EpiPen has not been used; even with ambulance arrival, the EpiPen is often delayed.

Ms BELL: What about from the point of view of the ant population? Is that on the rise or is it declining? Is it being treated at any level? Have there been any controls around that?

Mrs Gudden: From a local level, in Tasmania, where we collect ants, people will say to us that the ant population is increasing. I personally don't believe it's increasing. I think that construction is increasing—so we're stirring up the nests and more people are exposed in that way. I might also add that, interestingly, what we have found is that this ant is a very resilient, tough ant. Having worked for the program for 14 years, we have areas that we map out that are hotspots for the collection of ants, and some of these areas are affected by fire. Within 12 months of an area being impacted by fire, we'll go back to check it out, and the surviving being that we always find there are jack jumpers. They go very, very deep into their nests and their survival rate is amazing.

Dr Le: The ants do like a degree of warmth, and they like it when there's a bit less overhead coverage. There's certainly been a hypothesis that the urbanisation and the warming climate may predispose an increase in the ant nests. They're very hard to eradicate as well, as any patient of the Adelaide Hills can attest; they can reduce them, but they always seem to come back. We don't have good mapping data, at least in South Australia, and it would be good to have those sorts of studies.

Dr Hissaria: There was a botanist who contacted us last year when we first conducted a wellness program in the Hills. She had a very interesting hypothesis that, for every degree rise in temperature—and we are seeing longer, warmer summers—there are more of these ants. Most importantly, we don't know about the actual number of them, but they are definitely a lot angrier and they're moving around more commonly when the temperatures are high. When we do the sting challenges, if we go in summer to pick them up we can find 10 of them within five minutes and then come back. Whereas, if it's winter they actually go inside their burrows and are not seen. So, even if the numbers have not increased, they are definitely up and about more during the warmer temperatures.

Mrs Gudden: Ants are certainly more aggressive in the warmer periods; that's when we get the highest rate of referrals, but in Tasmania our referrals are throughout the year. I wouldn't say they are increasing heavily, but there's a slow increase in our referral rate.

CHAIR: Does insect repellent keep them away?

Mrs Gudden: No—short answer.

CHAIR: You're not going to get a job with tourism in southern Australia!

Mrs Gudden: When we collect ants we do use an insect repellent; we use Aerogard on our clothing. We're trying to keep our staff out there safe, because we have had a staff member have an anaphylaxis out in the field. That was as long time ago, but it has happened. We have very strict regulations around the way that we take our staff into the bush and protect them. We wear a lot of protective clothing, but, as people have said today, they will sting you through denim and they will sting you through leather; they will hunt you down if you have an allergy.
I'm saying that lightly. I am not a clinician; however, we do see that. If I were to stand in the middle of a nest and somebody who has an allergy were to stand near a nest, they would go towards the person with an allergy.

CHAIR: Who was your volunteer who did that experiment?

Mrs Gudden: No—not proven.

Ms BELL: Are you suggesting that these ants have an allergy radar in-built?

Mrs Gudden: Well, I don't know. As I said, I'm not a clinician; I'm only going on what we see and certainly the information that we hear from our patients.

CHAIR: But she is writing a horror movie!

Mrs Gudden: They're pretty scary-looking!

CHAIR: Thank you for giving us another reason not to do the gardening! I thank you for coming today and particularly for coming from Tasmania as well. It's been very useful because, as I've said, we've had some evidence in relation to tick allergies but it's essential certainly in relation to ants but in relation to insect allergies as well. So that has been very instructive. Thank you very much for your time. You will be given a copy of the *Hansard* transcript. If there are any corrections needed, could you let our secretariat know by 28 February.
CHRYSSIDIS, Mr Themis, Managing Director, Dietary Hawk

[11:26]

CHAIR: Welcome. Thank you very much for making yourself available to appear. This is just a formality, but I am required to remind you that these are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may in some circumstances be regarded as a contempt of parliament. The evidence you give today will be recorded by Hansard and will attract parliamentary privilege. Thank you for your contribution to the inquiry. I invite you to make a brief opening statement before we move on to questions.

Mr Chryssidis: Thank you for the opportunity to provide a statement and to appear as a witness on this very important public health issue. I am probably going to offer a slightly different perspective to the previous witnesses. I think it's worth noting that the difference is that, in their instance, a sting is unpredictable and they focus mainly on reactive methods of management, whereas I am going to approach this from a food allergy perspective where, once an individual is diagnosed with a food allergy, the focus should be on management strategies to reduce the risk of adverse reactions.

I became a dietician not to educate Australians to eat in any specific way. I became a dietician because I love food and I wanted to spread this joy to as many Australians as possible. I have always appreciated how attitudes and human behaviour impact on our dietary intake and food decisions. The first degree I completed was in fact a Bachelor of Psychology, because I recognised the importance of behaviour change on health and I wanted to spread a positive food message around Australia. I then completed a Master of Nutrition and Dietetics and quickly realised my passion for nutrition, cooking, food and psychology provided me with a unique opportunity to inspire Australians of all ages to cook, eat and live a healthy and fulfilling life.

Sprout Cooking School and Health Studio in Adelaide was born. Through Sprout we work with hundreds and thousands of individuals around Australia. This has allowed me, through my love of food, nutrition and psychology, to personally work with many individuals who have eating disorders, allergies, gastrointestinal conditions and other dietary requirements on a regular basis. It opened my eyes to the huge impact that strict eating patterns or dietary requirements have on many individuals' quality of life. The social isolation and social anxiety for individuals who are unable to dine out and eat with confidence is significant and demoralising.

Most Australians eat, on average, three to six times per day. We take the ability to eat what we want when we want for granted. Imagine having a life-threatening dietary requirement that means you have to think every time you eat out whether it's worth the risk. Even worse, imagine caring for a person who has a serious dietary requirement, such as a child, a disabled individual or an older relative who cannot communicate and doesn't understand the seriousness of their dietary needs. The anxiety felt by a primary carer or relative can be debilitating.

Now imagine you are already hyperaware of your dietary needs and your anxiety levels are high and then you go out for dinner only to feel disrespected and embarrassed by the venue's staff due to their lack of knowledge and training in the area of dietary requirement management. Or, worse yet, imagine ending your night in the emergency department. Your anxiety and stress have been validated, and you're unlikely to eat out again—or anytime soon. Your social anxiety increases, social isolation continues and you lose the basic right to enjoy a meal with friends and family. This scenario is far too common.

However, on a positive note, this is entirely preventable and manageable. Basic education and training will reduce near misses, save millions of dollars in hospital admissions and reduce anxiety and stress for individuals who have a dietary requirement. Chefs, restaurant managers and owners, childcare workers, schoolteachers and many more people who handle food and interact with individuals who have dietary requirements have all acknowledged that this is a major area of concern and an area that they want and need assistance in.

As stated in my initial submission, prior to Dietary Hawk's dietary requirement training programs, there were no training programs designed specifically to assist food services to manage consumer dietary requirements that covered a broad spectrum of dietary needs. One in four Australians with a food allergy has experienced a reaction due to their dietary requirement not being taken seriously by a food service, and 41 per cent of food allergy reactions occur in schools, among children. Dietary Hawk now provides a training solution created by dietitians and chefs for food services, including managing allergies, coeliac disease, food intolerances and religious and personal preferences.

I'm a dietician, a food lover, a cook and a business owner. I know and I see every day how food nourishes our body, our mind and our soul; how food connects us; how food defines cultures; and how food is central to celebrations and to building memories. There is no doubt that we are all privileged to live in Australia. However, currently individuals living with a dietary requirement simply do not receive the support they need and the respect
they deserve and are unable to enjoy things that many of us take for granted. I love food and I understand nutrition and food business, and we won't stop until every Australian has the right and the ability to eat with confidence.

CHAIR: Thank you, and thank you for your written submission, and obviously the passion for what you're doing. Questions?

Ms BELL: Thanks for coming in today. This is an area of great interest, particularly when it comes to food service providers. We heard from a gentleman in another city who, sadly, lost his wife because she was given a meal at an event in a large hotel, even though her allergies had been flagged. So, this is a great risk for people who are dining out, which is very common. How do you see standards being put in place to prevent that sort of thing from happening?

Mr Chryssidis: It is a huge problem. We've had individuals come to functions and leave and say, 'Thank you very much', and we get constant feedback showing their appreciation for the amount of care taken to meet their dietary needs—individuals literally wiping away tears after functions, saying: 'Thank you; I haven't been out for so long. However, we knew your organisation was catering for this function. It was the first time I'd been out in months.' At the end of the day, I think it's going to be market driven. I think it has to be confidence based. I think consumers need to be able to quickly and easily identify venues that have done comprehensive and credible training programs and have practices in place within their venue to meet their dietary needs, and I think that needs to be communicated to the public. We have a step above our training programs now where we actually certify food services and people can become Dietary Hawk certified, and that can then be used to communicate with the public. If an individual knows that they have a dietary requirement, they can go to a Dietary Hawk certified venue and feel confident that their needs are understood and will be comprehensively met.

Ms BELL: Does that mean there will be particular stations for food preparation types, whether it be for coeliac disease or for anaphylactic reactions, or non-seafood areas? How does that work in a commercial kitchen setting?

Mr Chryssidis: Quite possibly there will be. I think the difficult part of this entire management strategy is the fact that every kitchen is different. Every kitchen will have a different menu. They'll have a different capacity to cater for different needs based on space. The way we approach it is that we ensure that the venue has created a management plan that is designed specifically for their venue. It might not mean that they actually have adequate space to have certain areas for seafood only and so forth but that they have processes in place whereby deliveries come only to certain locations or perhaps dietary requirement meals are processed before other meals, or comprehensive labelling. One of the first witnesses referred to the ability to quickly and easily understand what's in food products, and these kinds of things. So, it becomes a management strategy, a management plan that the food venue, based on the training they've received, should create and implement within their venue. That has to be slightly flexible. The training needs to be consistent, but the management strategy needs to be flexible and adapted towards each venue.

Ms BELL: Would you say the labelling for the food that's delivered from wholesalers to a restaurant setting or a food service setting is even more inadequate than the labelling in a supermarket environment?

Mr Chryssidis: Not necessarily. Food products that are packaged have to abide by the same rules as any other product delivered in a supermarket setting. When there's a lot more fresh produce, perhaps bread and those kinds of products where wheat is one of the common allergens in Australia, then delivery can be difficult in terms of managing things like cross-contact. It comes down to having adequate delivery space and specific delivery locations for specific foods containing certain allergens. Again, that's part of the management strategy. It is manageable. We manage it at our venue. It comes down to education—I think that is the biggest problem—and it comes down to recognition of how serious this issue is by individuals who simply have not had any training in this area at all.

Mr ZAPPIA: Mr Chryssidis, I'm curious: what sort of response do you get from other businesses to your education program? Is it something you're detecting a willingness to take up, or is it difficult to get through to them?

Mr Chryssidis: Great question. Initially it's not necessarily the easiest conversation, because people don't necessarily don't know what they don't know. That's the challenging part of this. We're dealing with a group of individuals who work very hard, they work long hours, they have tight budgets, they don't have a culture of professional development, training and education, so we're having to shift that culture. We're doing it in some areas. I think the certification trademark is going to assist with that as food venues can then turn around and use this to promote the level of training they've got as an opportunity to market their business.
We are now seeing hotels start to open conversations with us. We've had stadiums start to communicate with us as well. We do think the tide is changing. It's going to take time, but I think a lot more people are open to it because they are now starting to see the danger that they're putting some of their patrons in. They also don't want the liability that comes with that.

Mr ZAPPIA: My other question doesn't really come down to you, but you might be able to help the committee with the answer. Places like TAFEs and hospitality schools, do you engage with them at all?

Mr Chryssidis: We have. We conducted a thorough needs assessment when we were determining whether or not this was an area of need. Obviously creating this program has been a major expense for us, so we wanted to do it right. We conducted a thorough needs assessment of the training programs currently available. Currently about one-third of a day, or a small section of a day, is assigned to managing dietary requirements, where basically people talk about how to create a vegetarian menu or something very basic like that. They don't receive any education in the space of allergies, intolerances, coeliac disease or anything like that. The people teaching the course also simply don't have the knowledge that is required, and they have openly told us that.

Mr ZAPPIA: That's interesting. Thank you for that.

Dr FREELANDER: Thanks very much; this is very interesting. Are you seeing this concept much like an RSA certificate that people would obtain prior to working in the food-serving industry?

Mr Chryssidis: Precisely.

Dr FREELANDER: So they would apply for their food-marketing or food-serving certificate. Have you costed that on an individual basis? What would be the cost?

Mr Chryssidis: We have two certificates that you can complete: one's called a Dietary Hawk responsible person and the other is called a Dietary Hawk responsible service. It does mirror the language used in responsible service of alcohol—again, this is on purpose because that's the demographic we're predominantly working with.

The idea is that you have to have a certain amount of staff complete a Dietary Hawk responsible person course, which is the longer course; it takes about 10 hours online. You have your key staff members, your full-time management staff complete that course. These are individuals who will actually create the management strategy that gets implemented into the venue. They'll ensure that the staff adhere to that strategy as they have a much larger base of knowledge. The Dietary Hawk responsible service course is a shorter course. It takes about two to three hours online. Regular staff would have to complete it to ensure they have the knowledge and skills to implement the strategy put in place by the responsible people. In total, we estimate, including certification as well, the average cost will be somewhere from $1,000 annually for a small venue through to around $5,000 or $6,000 for a large more-than-100-people venue.

Dr FREELANDER: So the charge is to the actual business, not to the individual?

Mr Chryssidis: Yes. If individuals do want to complete the course, they can do that and take the certificate with them to a venue. The short course is $35 and the longer course is $249.

Dr FREELANDER: Does part of the longer course include the first-aid management of anaphylactic or allergic reactions?

Mr Chryssidis: It does not include that. It only includes the basic knowledge that is required to understand the seriousness of an allergy—and obviously the other dietary requirements we also cover, coeliac disease and so forth—as well as the skills and the practical strategies required to implement and manage dietary requirements within the food service. We are talking about a demographic of people who work in a very practical manner, and the course is designed to be very practical in that regard.

Dr FREELANDER: And that would also include the dietary management of certain religious—

Mr Chryssidis: Absolutely. Yes, it covers all of those: allergies, food intolerances, coeliac disease and religious and personal preferences too. And that's important, because it then gives the business an opportunity to take this information and hopefully turn it into revenue for their business in the longer term as well.

CHAIR: I thank you for your evidence today; it's been very useful for the work of our inquiry. You'll be provided with a Hansard transcript of today's proceedings. If there are any corrections, you can let our committee secretariat staff know by 28 February. Thank you very much for your time and your submission.

Mr Chryssidis: Thank you.
NEWMAN, Dr Pooja, Founder, Globalaai

[11:42]

CHAIR: Welcome. Thank you for joining us this morning. I'm required to remind you that these are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter. Today's proceedings are being recorded by Hansard, and do attract parliamentary privilege. Thank you for your written submission. You've highlighted a very important area of allergies that I don't think any other submitters have raised directly with us, so thank you for that. I now invite you to make an opening statement.

Dr Newman: Sure. Thanks so much for having me today. I understand that this committee has been looking at impacts, costs and access to allergy support. I thought I'd spend this time talking to you about a story of an Australian woman who grew up in the eighties at a time where allergies weren't well-defined and there wasn't a lot of community awareness around anaphylaxis.

She had her first anaphylaxis in her late 20s, and after that was diagnosed with peanut and tree nut allergies. She spent a decade studying—that was an extensive and expensive decade—where she worked and studied clinical medicine in hospitals that prolifically used latex consumables and gloves, and specifically powdered latex gloves. She saw her career cut short due to occupational latex anaphylaxis. Had she perhaps been flagged as being atopic on a pre-employment WHS screening, had she used nitrile gloves instead, she may have been able to keep her career in radiation oncology. Because of her allergy, she faced cruel marginalisation and discrimination from unacceptable ignorance—and this included people within the medical community.

Latex allergy goes far beyond avoiding latex gloves. This protein cross-reacts with some fruits, so when she ate a banana, that put her into the high-dependency unit for a week. When she went to a very prominent music concert there was a significant and unexpected release of gigantic latex balloons without warning into the crowd and she suffered anaphylactic shock. Despite remembering to carry her own medication, the ambulance was significantly delayed, because of the extensive number of people who attended that concert. First aiders at the venue, on site, did not have any other EpiPens. She was lucky to escape hypoxic brain damage or death. Having survived over 30 anaphylactic reactions in her life, she hoped perhaps this time there would be change. The woman in the story is of course me.

As this inquiry has heard extensively, there is a very big need in this country to listen to the small organisations like ours, to consider all allergy stakeholders and to make simple yet significant changes that can ultimately protect, improve and save allergic lives in this country. This committee has the opportunity to consider high-impact, low-cost legislative changes. I don't think you've yet spoken about latex allergy. Such initiatives in terms of legislative change have the power to make this country a world leader, rather than just having the label as being the allergy capital of the world.

The prohibition of latex gloves in emergency care, health care and food service is considered and used in many states of America and should be brought to Australia to not only further prevent people from developing latex allergy but also protect those who suffer. In legislation, it's time to consider banning latex consumables and to limit the public release and display of latex balloons.

ASCIA policy—and you've heard from so many allergy experts in this country, many of whom are affiliated with ASCIA—supports general EpiPens. However, this isn't backed by international legislation. Our advocacy work with Safe Work Australia eventually translated to a change in their model code for first aid in workplaces. These are the stations that we would like to see, in this hotel, in the courts and across the road, in Chinatown where there are all those restaurants.

It was spoken about earlier today how schools in South Australia eventually got policy last year, which has been present for over a decade in the eastern states, as a result of ministerial directives from coronial inquests. It only arrived in South Australia last year. We have it on good authority that essentially meant the schools got one EpiPen. In terms of the geographical map of each school, Globalaai doesn't believe that that is adequate and that is adequate in terms of providing general use support for people at risk of anaphylaxis.

Now is our chance to communicate in a much more meaningful way to those who live with allergies. It's time to properly demonstrate good social inclusivity and protect people who live at risk of anaphylaxis. Show compassion and allow them to live rich, full lives free from heartache, frustration and isolation.

CHAIR: Thank you, Dr Newman. That was a wonderful presentation. You mentioned in your evidence something that was happening in the US that's not happening here. Could you just expand on that?

Dr Newman: They have model legislation. It's just recently been brought in in the state of Hawaii. It prohibits the use of latex gloves in emergency care, health care and food service.
CHAIR: Across the board?

Dr Newman: Yes. If you're a latex allergy sufferer, for example, you wouldn't know if that plate of food had been prepared by somebody in a kitchen using latex gloves.

CHAIR: Do you know the incidence of latex allergies?

Dr Newman: Back in the eighties where there was a prolific use of latex gloves, up to 30 per cent of health-care workers developed latex allergy but also children—

CHAIR: Did you say 30 per cent of health-care workers?

Dr Newman: Up to 30 per cent, yes. They would have some form of latex allergy. Latex anaphylaxis in itself is rare, but there is actually some evidence of that in South Australia. Recently, when the new Royal Adelaide Hospital was stocked with latex gloves there were more nurses anecdotally who developed a painful rash and difficulty working.

Dr FREELANDER: According to this presentation, contact allergy to latex is quite common?

Dr Newman: Yes. In a very small proportion of people that progresses to a wheeze, respiratory asthma symptoms and anaphylaxis.

CHAIR: What's the alternative?

Dr Newman: Vinyl and nitrile, in terms of gloves. Johns Hopkins were actually the institution in America that formed and founded the latex glove, and they were the first ones to remove it. So it came in for universal precautions. However, because of the rate of allergy, they removed it.

Dr FREELANDER: One of the problems with use of EpiPens is the very short shelf life they have. Have you looked at the cost of putting one of these stations in different areas? Have you got any comments on that?

Dr Newman: Yes. Australia has legislation to support general-use devices. Anyone can go to a chemist and purchase an EpiPen for $100, and they will last somewhere between 12 months and two years, depending on what sort of expiry they have. We don't believe that is an arduous financial burden for a food business, for example, to stock an EpiPen that's in date in the event of either first-time anaphylaxis or anaphylaxis requiring a further dose before an ambulance arrives or if there is a delay in seeking help, because it can be life threatening. But I suppose our vision as a social charity is that this is a constant reminder for people who work in that business to do what they can to keep people safe.

Dr FREELANDER: But have you actually costed having a unit like that in schools, for example?

Dr Newman: Yes. We've put out almost 100 stations in the last couple of years, all over the country, to schools, restaurants and offices. Our station—we're a not-for-profit—costs $60 for the box, and then you need to purchase the devices on top. In America, Mylan provides free devices to schools.

Dr FREELANDER: In the boxes, is it just one EpiPen?

Dr Newman: That's left to the individual organisation to make a decision.

Dr FREELANDER: So they would have to be responsible for making sure they're up to date?

Dr Newman: Yes, so they can go to the chemist and have a discussion about EpiPen. Usually, within Safe Work standards, there is a first aid officer within every workplace who is already EpiPen trained.

Dr FREELANDER: Have you looked at the different costs involved in using non-latex gloves and other equipment?

Dr Newman: The reality is that most Australian health care is now using latex-free gloves—nitrile gloves. It's just about taking that extra step and making sure there are no latex gloves in health care and that the sterile gloves, for example, are nitrile, not latex. On the supermarket shelves or at Bunnings sausage sizzles, unfortunately, the latex gloves sit next to the latex-free. They're of a similar price, and they serve a similar function.

Dr FREELANDER: So the cost to change over wouldn't be huge?

Dr Newman: No. In fact, there could be cost savings. If you have a patient arrive to a healthcare service with a latex allergy, you wouldn't need to have a specialised trolley or a specialised room. If you only stocked one single item on your imprest and told your supplier you were only accepting latex-free consumables, there would be health savings, as well as WorkCover costs, obviously.

Dr FREELANDER: Thank you.

Mr ZAPPIA: Dr Newman, you referred to some legislative changes. What did you have in mind as your priorities for legislation that could be changed?
Dr Newman: We advocated for Safe Work Australia and the model first aid code for workplaces to include
the provision of allergy safety—so having an EpiPen in a workplace in the event of an anaphylaxis. They also
took one step further and included a Ventolin puffer. We would just like to see that dropped into state legislation.
In addition, we'd like to mirror the American legislation that just prohibits the use of latex gloves in emergency
care, health care and food service. That would put us as a world leader.

Mr ZAPPIA: Currently in Australia, there is no legislation that refers to that?

Dr Newman: No.

Mr ZAPPIA: Whereas the Americans have banned it?

Dr Newman: The Americans have been banning it, yes. We have come a long way. We just need to take that
last step.

Mr ZAPPIA: What's Europe done?

Dr Newman: I'm not entirely sure what they have done around the latex allergy. I could get back to you.
When Obama was in, there was a lot of push around. Obamacare was proactive around allergy safety in America,
providing schools with free EpiPens.

Mr ZAPPIA: Just to get this clear, you were saying earlier that, if someone has used latex gloves in
preparation of food, the allergy can in turn be passed on to the consumer of the food.

Dr Newman: Yes, particularly someone like me who is anaphylactic.

Mr ZAPPIA: Are the allergy reactions severe? If I were to say some allergic reactions are much more severe
than others, where would you rate them?

Dr Newman: For me, as I have anaphylaxis to latex, I'm probably lucky to be alive. There are some wonderful
allergists here who help to keep me empowered with what I need.

Mr ZAPPIA: So we're not just talking about some minor discomfort?

Dr Newman: No. There is a spectrum: having a rash, a painful rash, a bleeding rash, asthma symptoms. If I'm
exposed, it results in anaphylaxis.

Mr ZAPPIA: How would someone—and I'm talking about someone down the line—who suffered an allergic
reaction to food be able to trace it back to the latex glove?

Dr Newman: I suppose that's why we have allergists who take extensive history and work out what it is
within the plate of food. Latex allergy is always something that they need to consider.

Mr ZAPPIA: Thank you.

Ms BELL: I want to ask a question around latex—whether it could possibly be expanded to first-aid training.
I believe some masks used during CPR training are latex. That's where you would have contact with your mouth
on the latex.

Dr Newman: Yes. Almost all rubber devices that are latex come in a latex-free alternative. If this country only
had the latex-free alternative, we would be miles ahead in terms of preventing other people from developing this
allergy but also easily protecting those who already have it.

Ms BELL: Can you think of any other area that it might expand to? Where else is it commonly in contact?

Dr Newman: Balloons and gloves are the really common ones. Gloves are used in a wide range of
industries—cleaners, hospitality staff. In those sorts of scenarios, there is no benefit in using latex versus latex-
free gloves.

CHAIR: Thank you, Dr Newman, for presenting this morning. As I said, we haven't heard evidence in
relation to latex allergies before, so you've been an important voice for those in our community who have such an
allergy. Thank you for being here. We will provide you with a Hansard of today's proceedings. If there are any
corrections or additions, let the secretariat know by 28 February. Thank you very much for your time.
NETTING, Dr Merryn, Private capacity

[11:58]

CHAIR: Dr Netting is a late addition, but I thought it would be useful to hear from Dr Netting, who has made a submission as a dietician. Welcome. Could you outline what your professional competency is?

Dr Netting: I am a paediatric allergy dietician. I work in the Women's and Children's Hospital in Adelaide and also in private practice—postdoctoral, and early-career NHMRC fellow. I hold a health practitioner fellowship.

CHAIR: You've made a written submission, but committee members won't have that in their pack today because you are a late addition, so I invite you to make an opening statement.

Dr Netting: Firstly, thank you very much for the opportunity to speak today and for adjusting the program to allow me to speak to you. I've been working with babies, children and families with food allergies since 1991 in public hospital and private practice settings, and I completed my PhD in prevention management and treatment of food allergy in 2015. I'm a member of ASCIA and a member of the National Allergy Strategy Steering Committee, but I'm speaking as an individual. I'd like to focus on individuals who have not been addressed by submissions by ASCIA or the NAS.

Firstly, the maternal diet during pregnancy probably does play a role in prevention of allergy. We know that the foods a baby eats in the first year of life, particularly babies with eczema, can reduce the risk of developing allergy later on by the time of the introduction of allergy-causing foods into their diet. You've heard a lot today about food allergy and how it's a challenging health problem in childhood, and how difficult allergen avoidance is for families. This forms the cornerstone of the management. On a practical level, this requires constant vigilance to ensure that every meal, snack and drink that a mother or family provides for their child is free from the allergen that they are sensitive to.

Many others have given evidence about the importance of timely diagnosis of food allergies and being seen by the right professional at the right time. In the context of food allergy after a diagnosis, nutrition advice and management is best delivered by a trained nutrition professional. Accredited practising dietitians are recognised as the professionals with the appropriate training and skills to do this. This also includes a focus on long-term nutrition for healthy eating and the prevention of chronic disease such as obesity, cardiovascular disease and osteoporosis.

Children allergic to staple foods such as cow's milk or wheat, or those with multiple allergies, can have poor growth compared with their peers and are at risk of developing other issues related to nutritionally inadequate diets. Mothers who manipulate their own diets while breastfeeding to manage their own diets have special nutritional needs. This is also in the context of a baby who is not sleeping well or of a parent having seen their child experience a severe reaction; we heard one parent speak today about her own experience of that.

Individuals facing long waits to see a paediatric allergy clinician may seek advice from unorthodox medical or other health practitioners. There is good evidence to show that the use of broad exclusion diets in children, particularly those with mild eczema, may actually lead to the development of severe manifestations of allergy, including anaphylaxis. In addition, in the absence of medical diagnosis, children with non-specific symptoms falsely attributed to food may be placed on diets they don't need to be on.

The last point I'm going to make is that infants and young children with food allergy are more likely to develop feeding disorders, including swallowing issues, food refusal and picky eating compared to their peers. Causative factors include early negative experiences with food, delayed introductions of foods due to parental fear of reactions and parental anxiety around feeding. Early recognition and intervention is very important for these children. They often require intensive and ongoing specialist feeding therapy.

We encourage the committee to think about things that have already been discussed today, like education and training for GPs, dietitians and maternal health nurses in early intervention and appropriate management of allergies—particularly early recognition of non-IgE mediated allergies, which we think are becoming more common. We need adequate funding to embed dietitians and other allied health professionals into allergy teams to offer appropriate and ongoing support, and we need appropriate research funding to enable us to further expand this field in Australia.

CHAIR: Thank you. We've probably got time for one or two questions.

Mr ZAPPIA: You touched on this towards the end of your statement, Dr Netting: if you were to recommend one or two priority things that you would like to see the government do, what would they be?
Dr Netting: I think the shared care model initially is really important. So that's adequate education and training for those people who are the first line. That would be recognising a baby or a child who may be presenting with allergy symptoms and getting a diagnosis early and being seen by the right team.

Mr ZAPPIA: What's stopping that from happening right now?

Dr Netting: I think part of the issue is the changing nature of food allergies in Australia. Food allergies have gone from being a condition that is uncommon to being very common. We're now seeing things like more non-IgE mediated allergies—so conditions like FPIES and eosinophilic esophagitis of children with proctocolitis due to cow's milk becoming more common—and they may not be recognised early. So early recognition and management is important. The way we see allergies manifest is changing, I believe.

Mr ZAPPIA: Thank you.

Ms BEL: I have some questions around the reasons for the rise of these sorts of food allergies. Is it actually increasing or is it because more people are seeking treatment for those allergies? What does the research tell us?

Dr Netting: There is very clear evidence that this is a real phenomenon, and Professor Allen's research has demonstrated that one in 10 one-year-olds in Melbourne have a food allergy, and one in 20 high-school-age children. The increase has been a real thing. Also we believe that we're seeing more children with multiple food allergies. In my practice I would very rarely see a child with a single allergen.

Ms BEL: Would the reason be the same in Melbourne as it would be in, for example, Brisbane? I won't say Adelaide because it is quite close to Melbourne and there are very similar geography and similar kinds of hay fields, I suppose, around for specific allergies. But would you say there's another underlying reason that more children have allergies? I haven't read all of Dr Allen's work, but I was at the hearing in Melbourne where it was talked about. It was said that it the wind direction and the hay fields or the wheat fields around Melbourne and that sort of thing made these allergies more prevalent in Melbourne. Is there any other reason? Is it additives in food? Is there research going into that?

Dr Netting: We could be here all day, as Professor Gold said. It's a very multifactorial issue. Part of it is that there has been a generational change in the types of foods we're eating. So there have probably been changes in our diets which have affected the microbiome in our gut, which can affect the way we develop allergies. The way we feel our babies has changed. We have a lot more Asian migration. All of these things have been shown to affect your likelihood of developing an allergy.

Ms BEL: I think it's good at this point to have a summary of your thoughts on that.

Dr Netting: I think what we need to do is focus on what we know we can do about allergy prevention. The National Allergy Strategy has some good clear progress in that. We need to support research into appropriate diets for pregnancy—that are active at the moment. The other environmental issues also need good research.

CHAIR: One question from Dr Freelander.

Dr FREELANDER: In an ideal world, any child that we suspect of having a food allergy should be seen by a dietician. Is that the case in South Australia?

Dr Netting: No. Not everybody with a food allergy would be seen by a dietician.

Dr FREELANDER: What percentage would be, would you say?

Dr Netting: That's a very good question. We have tertiary-level allergy dieticians who would work at the Women's and Children's and at Flinders, and we have several dieticians working in private practice.

Dr FREELANDER: Do you take referrals from general practitioners?

Dr Netting: Yes, in private practice. But at the major hospitals, no, we'd only take referrals from referring doctors.

Dr FREELANDER: Is there a significant cost involved in private practice?

Dr Netting: Yes. That is funded by private health unless you have an enhanced primary care plan, where you can access Medicare funding towards that.

Dr FREELANDER: But there's a gap.

Dr Netting: There's a gap; that's right. In addition, not all dieticians are experienced in paediatrics, and not all paediatric dieticians are experienced in the complexities of managing food allergy. So there's a big gap in training there.

Dr FREELANDER: Thank you.
CHAIR: Thank you. We'll give you a copy of the Hansard transcript. If there are any errors or corrections, could you let us know by 28 February. Thank you for your time.

Dr Netting: Thank you very much.

Proceedings suspended from 12:10 to 13:07
KERR, Ms Monique, Director; Manager, Family Support Services; and Psychologist, Allergy Support Hub

WARNER, Ms Emma, Director and Psychologist, Allergy Support Hub

Evidence was taken via teleconference—

CHAIR: Welcome. These are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter. Today's proceedings are being recorded by Hansard, and your testimony does attract parliamentary privilege. Thank you for the submission that you've lodged on behalf of the support hub. Would one of you like to make an opening statement?

Ms Kerr: Thank you for having us here today. It's a pleasure to be here. As you will see from our submission, we're a small charity with big plans. We set up Allergy Support Hub 18 months ago with the mission of improving the quality of life for families managing allergies. We have a team of two psychologists and a nurse, and we're all current associate members of ASCIA. We saw that there was a real gap in on-the-ground services available when it comes to managing life with allergies. As a parent this can come in many forms: for example, if my child has a dairy allergy, how can I keep them safe but also take them to playgrounds where other children might be wandering around? Can I take them to birthday parties? How can I talk to people? For some parents and children, it becomes a genuine battle to leave the house and to manage the anxiety and stress around the risk of exposure or wanting to live their lives.

Our service has two arms: clinical services and family support services. On the clinical side, we provide psychological counselling, where a registered psychologist works with individuals to help them address and manage the multitude of complex issues that are often associated with managing food allergy and other allergic conditions. These include early adjustment to having a child with a chronic condition, worry and stress, guilt and grief. Family support services are our walk-in service aimed at providing social and emotional support, resources, grief interventions and psychoeducation. Here we're aiming to get in early really and support families to manage their allergies and mental health effectively before it escalates into larger issues. Our approach is to empower families to advocate for themselves by providing them with the tools and skills to cope and build confidence to live life with allergies. We feel we're doing really important work and that there is a need to increase the level of support available.

On the clinical side, we've had a steady increase in referrals from our service as time has gone on. We've had 10 referrals this month alone, and there's a real unmet need. On the family support side, we [inaudible] frontline practical advice and psychological support to parents and children who find it hard to integrate management of their allergies into everyday life and navigate life changes—maybe a new baby or starting school, for example. These aren't minor worries; they're real issues that dominate family life. Our support groups consistently feature mothers in tears finally able to share the challenges that they're facing with people who understand.

One of the main challenges for us is that, until the problem escalates to the point where there is a mental health plan in place, there is typically no funding available. While we see a path to taking on another psychologist, given the level of referrals coming in, immunologist and GPs and others, we would really love to be able to grow our support and early intervention services, but, at this stage, we don't have a funding model to support that.

Allergy & Anaphylaxis Australia said in their public hearing that the need for psychological support is apparently one of the most pressing issues they're trying to address. We couldn't agree more. Ultimately there is a growing and unmet need for practical and emotional support, education, psychoeducation and mental health services for people dealing with allergy. We are doing our small bit and we're really thankful to be invited here today to help explain the importance of this issue to the committee.

CHAIR: Thank you very much. What was the genesis for your support group? Is there anything similar or did you think there was a complete absence of any support network in Perth for families?

Ms Kerr: I think for us there was a lack of on-the-ground support. There is definitely support available in general across Australia, but Emma and I are both mothers of children with allergies as well as psychologists and when they were diagnosed with allergies, we felt that there was nowhere to go on the ground to find someone in that supportive environment to connect with others going through the same experience. Emma and I both actually did reach out to try and find these quite extensively which led us to a lot of research internationally as well as across Australia around mental health and support services with allergies, and we just didn't find anything particularly locally here in Perth.

CHAIR: Could you identify what you think the greatest need for parents is? It's obviously support generally but is it during the diagnosis stage or during the ongoing management stage or is it a bit of everything?
Ms Kerr: I would say it's all the different life transitions. We see a real peak at different points in people's lives. There's post diagnosis, which we refer to as newly diagnosed, and there are a lot of other aspects: when they're toddlers, when they start going to first birthday parties. What we've come to understand anecdotally and through research we've done is that individuals and families need [inaudible], particularly post anaphylactic reactions, as the child gets older and at times when there is significant change for families, including transition times like starting kindy, moving from one school to another and the transition to high school. We also see adults, particularly adults who have had allergies all their life but also adults with newly diagnosed allergies that have really impacted their life.

Chair: Final question from me: you talk in your submission about allergies in schools and making sure there are consistent national standards. I'm interested in how well you think the school system in Western Australia supports children with allergies. My perception, based on the little bit of evidence we've had this morning in Adelaide, is that there is significant variation between the states, South Australia probably being a little bit late to catch up. How do you perceive the situation in WA?

Ms Warner: We would tend to agree with that. The schools have to have plans in place, but we have noticed that it varies between schools in terms of how they manage and support children in schools. They have to have their care plan in place. But we've found that there are nuances in terms of whether the plan might be held in the administration building or if it's in the classroom. These kinds of nuances, I suppose, are what can potentially cause anxiety and worry for parents, because they don't know what they're going into and what they might need to address with the school. I think schools could probably benefit from more training in terms of the management of food allergies.

Dr Freelander: Could you try and distil for me what different service you are offering to the allergy community with your Allergy Support Hub.

Ms Kerr: We're a charity and we offer psychological counselling—one-on-one counselling sessions that people—almost all of our clients—usually access through a mental health care plan from their GP.

Dr Freelander: That's not really a charity; am I right? You're still receiving a fee from Medicare for providing that. Is that right?

Ms Kerr: Could you say that again. It was a little bit unclear.

Dr Freelander: You're seeing people through the Medicare mental health support plan provided by the GP, so you're actually receiving a fee.

Ms Kerr: Yes, absolutely. We're a charity. We're a not-for-profit. As with all not-for-profits, our funds go straight back into servicing our community. We use the mental health care plan, so when people come in they either have a small fee on top of the mental health care plan or it's bulk-billed. We use that funding to prop up our family support services, our seminars, our workshops and our support groups.

Dr Freelander: Do you receive a salary through the Allergy Support Hub?

Ms Kerr: Not at this stage. Emma and I have both volunteered for the last 18 months, as have our colleagues.

Dr Freelander: So you don't receive any money from the Allergy Support Hub?

Ms Kerr: No. At some point in the future we would love to set up as a proper charity with salaried members, as formal charities have. But at this stage it's been a real labour of love. The important thing was just to get it off the ground. We saw so many families in need of psychological counselling in this space, so we just got started. The counselling funds the small room that we have in the City West Lottery House in WA. We're very fortunate in WA to have the Lotterywest program. It helps charities out.

Dr Freelander: Presumably you're seeing different groups of kids, from the very young to adolescents.

Ms Kerr: Yes.

Dr Freelander: Have you been able to identify any specific target groups that you think should be given extra support?

Ms Kerr: Yes. I would say there are a few target groups. It really goes to the span of the lifecycle of allergies. There are families who have very young children, and they're often in quite a lot of crisis post diagnosis. We also very regularly see them in the toddler years, when they're trying to manage how to get out of the house when you have a toddler who has allergies. Toddlers are incredibly messy, and motherhood is incredibly challenging and isolating at that time. We get a lot of school-age children who have had an anaphylactic reaction. They are coming to understand their own life and what it means in the wider context of the world; when they have an anaphylactic reaction that causes a lot of trauma. Then we also see teenagers and adults. We probably focus more...
on early childhood at this stage, just because of the sheer need and the amount of people going through allergies. But, yes, we see everybody—babies through to adults.

**Dr Martin:** My question is in relation to the early intervention—the phase or the part of the program you offer that doesn't currently have any funding for the client, as your organisation calls them. What does the early intervention entail exactly?

**Ms Kerr:** At this stage it's been a bit of finding our feet in terms of what people want and need. We looked at the Boston Children's Hospital. They have a psychologist as part of their clinic at the hospital. We've based it a little bit on that model and on a lot of research looking at what sorts of support and early intervention assist families with chronic conditions. We offer a support group, which, in the allergy space, runs almost like a playgroup, because a lot of families don't get out of the house. They feel like this space is safe. We've got toys for the kids. The parents come and connect, and the children play. They get a chance to engage. We also run workshops for families. We run a 'newly diagnosed' workshop, which is more of a group session, covering off what to expect in those early post-diagnosis emotions and how to start talking to your children about their allergies, engaging with them about their allergies, from that real social and emotional—

**Dr Martin:** Is there any research available on providing psychological therapy to parents of children with allergies or to children with allergies?

**Ms Kerr:** Yes. The research pretty much all comes from the US. In the US there's been a lot of research looking at the mental health of individuals with allergies—children, adults and families. That all shows there are much higher rates of anxiety, specifically, and a lower quality of life than in the normal population. There's very little research in Australia. We're actually working with the local hospital to start to conduct some of that research, from a rates perspective and also from an intervention perspective—which interventions we're using are effective.

**Dr Martin:** In terms of methods that you're using for psychological therapy, is it a developmentally-appropriate cognitive behavioural model that's used for the anxiety?

**Ms Kerr:** I'll pass you on to Emma. She's our clinical psych.

**Ms Warner:** Sorry, can you repeat the question.

**Dr Martin:** My question is about the approach or the techniques that are used. Is it a developmentally-appropriate cognitive behavioural approach that you take to reduce anxiety in children that present with allergies or parents that present with children with allergies? Is it CBT?

**Ms Warner:** Yes, absolutely; it's a component of that. I do graded exposure. This is something that I liaised with a professor at Boston Children's Hospital on, about how they were providing therapy to people that were accessing the service there. I consulted with them around what was best practice. In our conversations we spoke at length about how graded exposure is really effective. To give an example, a child might present with a dairy allergy, having just had an anaphylactic reaction. What can happen is that the child starts to deny having their safe foods. A safe food is something that they're not allergic to. But they're so worried that their allergen might be in their previously known safe foods. So, as part of the therapy, what I do is I help the child to regain control over being able to have their safe food again. That is something that we typically see post anaphylactic reaction—that really restricted eating. So the graded exposure really helps because it allows the child to be exposed to a small amount of anxiety but it only elicits enough that they're actually able to complete the activity or eat the food. It's a building block I've prepared, so I use it for food but I also use it for activity based—if a child is worried or scared about eating out, so where a parent has come to us and said, 'They won't eat at their local restaurant anymore. We've previously been able to do that,' the graded exposure really helps to address that, and it's been extremely effective.

**Dr Martin:** Do you work the parents at the same time you're implementing programs directly with the children?

**Ms Warner:** Absolutely. What I do usually is I'll see the parent at the beginning in conjunction with the child. It's a very practical approach, because that's what I think is the most effective. So parents will sit down with me and talk with me about—I suppose you can look at it as a domain. So we look at their home life and out-of-home life in terms of where they might be avoiding, so we will only target the domain that's having the most impact on that family. So the parent works with me, and then I work alongside them with the child about how we might overcome the anxiety around the food allergy.

**Dr Martin:** I think that's very important, because I think that a lot of parents could project their anxiety onto their child in situations where there has been an anaphylactic event or where a parent has anxiety about their child's allergies. Do you have a manual that you use when you implement the therapy, and have you done any review of your program? I'm just thinking of how you might be able to fund the service in future and that having
some research or evidence behind the efficacy of what you're doing—should it be something that is actually improving the outcomes, the psychological wellbeing of the parents and children—it would be very good (a) to have it manualised, and (b) to have it reported.

Ms Kerr: We completely agree. We are in the process of probably having to take on another psychologist as we're getting so many referrals. In terms of the manual, this is something we're working on at the moment, and a training program for somebody that we bring on. In terms of research, absolutely. If you've got a couple of minutes I'll just run you through. When we first started up there was a little bit of local research—WA based, and a little bit of Australian research—into chronic conditions and what happens to families in that, what you call, passion of coping post diagnosis. That's around the emotional crisis following the diagnosis. There might be denial, grief, self-doubt, anxiety. Then, with time, there's going to be a process where control is regained through seeking information, attempting to establish new routines, integrating how it affects your life and slowly developing those coping skills. Then, as more time passes, the coping skills and confidence start to increase: new routines and conditions are established and that diagnosis starts to actually be accepted into the family life and the parental roles, and that sense of normality is restored. It's a particular model that they researched in parenting children. As I said, it's more for people for asthma and diabetes, but anecdotally it fits. Different families go through that in a different way—some might get stuck at the emotional crisis, others might move through it really quickly but then be set back by a severe reaction. The interesting part of that research for us is that it was showed that individuals of families moved through this cycle more effectively and quickly towards coping when they're provided quality support and education. So, for us, we're starting to already collect data in the work that we do. It's testing that model and testing if the support interventions that we're using are making a difference. Then we're working through PCH to try and start actually doing research as soon as we can.

Dr Martin: Thank you. That sounds really promising.

Ms Bell: I want to ask a question around labelling. In your submission you say:

Our personal and professional experience combined leads us to assert that food allergy labelling in Australia is confusing and difficult to understand...

Is that based on feedback from the parents that you're dealing with? That's my first question. The second one is, you also assert that there is not clear labelling in food service, and we have varying kinds of views around that, which we've heard today, so I'm wondering if you can tell me what you think the gaps are, on the food labelling, in food service?

Ms Kerr: My understanding, based on the research I've done and on families that come to us and say what their challenges are, is that there's that clarity around 'may contain' or 'may be processed in the same factory'. I think there are some guidelines around that—I think I've read about this, by Katie Allen, about that labelling and specificity—but there's a lot of misunderstanding in the community about what those exact intricacies are. As a result, we see lots of families calling organisations to see if they are processed on this sort of line or that sort of line. So from that aspect we find it not to be that clear in Australia. In terms of restaurants, from both personal experience and experience through our families, there are not clearly marked allergens on menus and staff are often not helpful, in terms of accommodating allergens.

Ms Bell: So it's not the labelling on the food per se but it's the labelling within the restaurant that you're talking about.

Ms Kerr: Sorry, did you say the labelling in Australia?

Ms Bell: The labelling of the food within the menu and in the restaurant as opposed to on the actual food that's delivered to the restaurant in packaging, which is different to retail packaging, for example.

Ms Kerr: I wouldn't confirm that this is for the entire area of food service. It's more with families overcoming their anxieties so they feel that they can eat as much food as they can within their realm. I don't know what food comes into restaurants, at that end, but I'm definitely talking more from a perspective of being in a restaurant and experiencing difficulty and a lack of necessary information. With families, essentially, our aim is to help them feel empowered and to be assertive, to put their needs forward in restaurants.

Ms Bell: It's just highlighted to me that there are two areas in food service. One is the packaging that's around the food when it's delivered, and the other is the additional burden around the menu labelling and the labelling inside the restaurant.

Ms Kerr: Yes. In submissions before, I think, you've heard the same thing, and I can imagine that is absolutely the case. But for the user's perspective, or certainly this is my message to someone with a nut allergy, if I'm in a restaurant and ask about nuts the answer I'll get is, 'It may contain traces.' It's a blanket response, and you don't know what that means.
CHAIR: That concludes our session. Thank you very much for your time today under what have been slightly difficult conditions through the quality of the audio.

Ms Kerr: Yes, sorry. We're getting a lot of feedback at our end too.

CHAIR: I apologise for that. But thank you again for appearing and for your submission. We will send you a copy of the transcript. Hopefully, this means we'll be able to read what each other said, even if we don't clearly understand it at this stage! If you have any corrections or comments on the transcript, please provide that to the committee secretariat by 28 February. Thank you both for participating.
MORTON, Ms Carly, Private capacity

[13:34]

CHAIR: Welcome here today. I need to remind you that these are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter. Your evidence today will be recorded by Hansard and does attract parliamentary privilege. We are very grateful that you've made the time to be here, because you have been through the most horrific manifestation of allergies. Hopefully, it's not too daunting an experience being here. We're quite friendly and nice most of the time, except when we're arguing with each other. Thank you also for your detailed written submission, which was fantastic. Would you like to make an opening statement?

Ms Morton: As you've touched upon, I'm really here today to speak as somebody who has direct experience of what is the worst possible potential outcome for a sufferer of anaphylaxis and that of course is death. My husband Glenn Morton passed away in 2018 after suffering an anaphylactic reaction to a bee sting while working on a remote mine site in Western Australia.

What I think is a unique perspective of Glenn's experience is that he was navigating the onset of anaphylaxis and how to manage that as an adult, so an adult dealing with the emergency room and the medical services that support anaphylaxis, or the lack thereof, and also as somebody who was active in the workplace, which I think is quite an important issue. From what we can tell there are increasing numbers of children being diagnosed with anaphylaxis and they will grow up to want jobs and be adults out in the world. We really need strategies and education so that workers and organisations can manage anaphylaxis effectively so that those people are empowered to take the best possible care of themselves while just going about the really ordinary business of going to work.

CHAIR: Thank you. In your submission the thing that struck me was how little education even he received about his condition. Just step me through that. He obviously was stung in his 20s—I think you said in your submission—for the first time, and that's what actually triggered the diagnosis. Did he get the diagnosis through a hospital or GP, or did he see an allergist?

Ms Morton: It was a very vague process throughout. Glenn was very fit and healthy, and he loved the outdoors, four-wheel driving, fishing—all those things. It came as a real shock when he had that reaction—he was in his late 20s at the time—to a bee sting. For the very first reaction he eventually was taken to an emergency room where he was treated. When I went to pick him up, the emergency room doctor said—and I remember this so clearly—'I don't think it's anaphylaxis, but we'll give him an EpiPen.' That attitude really made us think: this isn't that important. It's almost like: 'I've got a bit of a headache, so I'm going to take some Panadol with me.' We didn't know a lot about anaphylaxis and we were not really given the impression that we should educate ourselves or be concerned. That to me wasn't a very precise diagnosis—it wasn't a diagnosis. When we went to the GP there was some reluctance to give an official diagnosis because the doctor hadn't treated Glenn, so he was relying on what we were telling him about the emergency room experience. He supported: 'Carry EpiPens—they're safe; you should have them.' But, again, no: 'This is a condition, and you must be careful.' That just continued through the second reaction that he had as well.

Ms BELL: Was that after the initial bee sting?

Ms Morton: No. We only learnt that such a thing existed after Glenn's death, in speaking to Allergies and Anaphylaxis Australia.

CHAIR: He was never offered the immunotherapy?

Ms Morton: No. We only learnt that such a thing existed after Glenn's death, in speaking to Allergies and Anaphylaxis Australia.

CHAIR: And you raise through your example the particular conditions faced by people working in remote regional areas. Obviously working in the mining sector it's a larger operation. But do you get a sense that their medical staff that support staff had any sense of how to treat an allergic reaction?

Ms Morton: We get the impression that the first aid was not particularly tailored to anaphylaxis. I should point out the disclaimer that the investigation is still ongoing. The Department of Mines is still investigating. We have very scant and very conflicting information on what happened to Glenn. What we have been told is that he was moved from where he was found—he was moved to the car and moved to a first aid post—which we know can hasten the venom's movement through the body. So, that was not an appropriate reaction, necessarily. We know he was placed in the recovery position and we were told he turned blue, and then the first aiders realised they had to intervene. That would, again, suggest to me that they weren't aware of how critical monitoring the
airways was for someone in Glenn's position. We were also told that they deployed a defibrillator, which didn't deploy correctly, because at that time he still had a pulse. So, again, to us it was perhaps a basic first aid response that in many emergencies would probably be the most appropriate response but there was maybe not an understanding of Glenn's specific needs and condition.

CHAIR: The other aspect of your submission—and I shouldn't editorialise, but I just find it remarkable that your GP didn't refer you up the chain to a specialist—is the management of the EpiPens themselves. He was never told that keeping it in a heated environment like the car, for example, could reduce its shelf life. But I noticed that you mentioned that one of the EpiPens he had was expired. And you refer to the shortage of EpiPens at the time. So, was that actually a factor? Had he sought to get another EpiPen and couldn't, because of the shortage? Or was he just thinking there wouldn't be any available?

Ms Morton: No. He was actually deployed to the mine site at very short notice and we noticed in preparing to go that the EpiPens were expired. That was how we discovered about the shortage. We went to about five different pharmacies.

CHAIR: So, you actually tried to get new ones before he left?

Ms Morton: We did, yes.

CHAIR: We were having this discussion the other day about how long the EpiPens last. Had they been expired for some time? Or was it relatively recent?

Ms Morton: I don't recall, I'm afraid.

CHAIR: But it is interesting that heat can affect them as well.

Ms Morton: Yes, which we weren't aware of at all.

Dr FREELANDER: Thanks so much, Carly, for telling us your story. I think it's a really important one that really makes us aware of how poorly anaphylaxis is managed in Australia. I'm interested in a couple of things. At any stage was Glenn, or you or his family, offered any education about bee sting allergy at any level—

Ms Morton: No.

Dr FREELANDER: given that he'd had three previous episodes of anaphylaxis?

Ms Morton: It was the third that was fatal.

Dr FREELANDER: So, two previous episodes.

Ms Morton: Yes.

Dr FREELANDER: At no stage, as far as you're aware, was any education or training or—

Ms Morton: No, there was nothing offered to us as the family, certainly. I don't believe that anything was offered to Glenn without us present, because I'm sure he would have told me. And not ever having come into contact with managing anaphylaxis before, we were very ignorant, to be honest.

CHAIR: Before we go on, I have just been reminded—so that we don't get ourselves into trouble—if the WA mines department is still conducting some type of investigation, we need to be a little bit cautious, so we might avoid asking about the specific circumstances about the final anaphylactic attack if that's okay and talk about general issues.

Dr FREELANDER: Sure. So this happened in 2018?

Ms Morton: Yes.

Dr FREELANDER: And they're still investigating?

Ms Morton: Yes. The coroner has made a final decision not to hold an inquest, which we have appealed unsuccessfully, and the department of mines' investigation is ongoing. They act instead of Worksafe, because it was a death at work.

Dr FREELANDER: So has the coroner offered any reason not to offer an inquest?

Ms Morton: The Coroners Act allows for an administrative decision to be made or—I'm not a lawyer; my terminology might be off, but I believe it's essentially because they saw this as a medical condition. I do have a copy of the letter if you would like to see it. But I can't explain well.

Dr FREELANDER: Did Glenn have any other allergies?

Ms Morton: No.

Dr FREELANDER: How are you going following this tragic loss of your husband? Have you been offered support?
Ms Morton: I haven't really had any contact from the mines and so forth. The main source of support—the only real source of support I have been offered—was when Maria from Allergies and Anaphylaxis did a radio interview that my father heard, then he rang them, because we hadn't heard of them before, and she got in touch with me about what they could do to support me.

Dr FREELANDER: Life is always easy in retrospect, but can you offer any suggestions of what you think should happen?

Ms Morton: For support for somebody in my position?

Dr FREELANDER: The overall bee-sting allergy continuum. What do you think we should be doing to prevent things.

Ms Morton: I think one of the really important things is to allow people to be educated and supported at diagnosis. As I said in the submission, I don't think that burden should come onto emergency room doctors, who have many things going on, but there needs to be a way for somebody, after they have been treated for anaphylaxis in an emergency room, to be connected with follow-up services—the immunologist and those supports, creating that connection, and helping people get educated about their condition. The other thing I think is important is having procedures in place for how people in the workplace manage their condition. In Glenn's case—I hope I'm not crossing the line with your comment about the ongoing investigation, but I believe his only obligation was to disclose the condition. Whilst disclosure is important, that's not an action that leads to results. So it's about: do we need procedures? Do we need people who are trained specifically to deal with that? It's creating a system where that person is safe when they go to work.

CHAIR: I think it's an important part of your submission. We do obviously focus on doing that in schools, in an environment with young people, but maybe not so much in the workplace.

Dr FREELANDER: I have one last question. When did you hear about the possibility of desensitisation?

Ms Morton: After being in touch with Allergies and Anaphylaxis Australia, which was probably a good year after Glenn's death.

Dr FREELANDER: Thanks so much for coming.

Ms Morton: Thank you.

CHAIR: Mr Zappia?

Mr ZAPPIA: I'm not sure I have any questions, Carly. I don't know what to say other than to very much empathise with your story and to express my sympathies to you for what you've gone through. I would have asked the same question as Dr Freelander: what would you like to see this committee recommend so that we can perhaps make a difference in the future? Is there anything else you can add from your experience that you think should be changed? Whether it's laws or practices, I would be interested in hearing what you have to say. You sort of answered that, but if you've got anything else to add.

Ms Morton: Probably the only other thing I would add is my experience with the coroner, notwithstanding I understand that is a Western Australian jurisdiction. The coroner's letter states that their primary purpose is to find the cause of death—which in Glenn's case was reasonably straightforward—and not to make recommendations. I think it's such a lost opportunity. We've seen that in the past. There was the Kylie Lynch inquiry. It's some years ago now, but there were recommendations made that we know haven't been fully investigated as to how we can implement them. Those sorts of recommendations and that knowledge will be in any state that has had to deal with an inquest of this nature. If there is a way we can take those recommendations and make something positive out of them, I think that would be a fantastic outcome.

Ms BELL: Thanks for coming all the way from WA, Ms Morton. I'm terribly sorry for your loss.

Ms Morton: Thank you.

Ms BELL: It's very sad. We've talked about education as having a really big role in improving community awareness and also how it's needed across very many sectors, including for first aid programs—where anaphylaxis should be part of a first aid course for clubs and workplaces—for general practice, for university medical students and for emergency ambulance officers, I suppose. Would you agree that having education across all of those sectors would help to remedy this problem that we have with anaphylaxis across the community?

Ms Morton: I think that, if we can be broader with getting that message out there, it is certainly a positive. To me, anywhere that a person with anaphylaxis is interacting with on a regular basis should know how to care for that person, so any of those institutions should probably have some awareness, particularly on the first aid side of things.
Ms BELL: I think it should also be highlighted that people are not always aware that they may suffer anaphylactic shock. If they're bitten by a jumping jack ant or have a bee sting, as in your case, they're not necessarily aware that they are allergic until that actually happens, which makes it more difficult for the patient and for the family.

Ms Morton: Definitely. If those first responders have been well trained in recognising and responding to anaphylaxis, that would give that person a better chance of surviving that incident.

Ms BELL: So it really would be a core unit in every level of education around anaphylaxis.

Ms Morton: I think so. For anybody that would deal with looking after somebody who has anaphylaxis—or, as you say, potentially has anaphylaxis—that would be very important. I think messaging is really important too, to give the weight of the potential of the condition, because that's something that we probably were let down on a bit. It was treated quite flippantly by everyone we spoke to. Even if that information was just out of our reach, we weren't questioning. We felt that this was not that serious. So it's delivering the information and how you deliver it.

Dr MARTIN: Did you go back to the same hospital or the same doctor the second time?

Ms Morton: The second time was the same hospital, yes.

Dr MARTIN: And they would have had records from the first visit?

Ms Morton: I would assume so, yes.

CHAIR: Thank you again for being here today. We really appreciate the effort you've gone to to be here. There's not much we can do about the past, but hopefully, with your testimony, this committee will be able to make recommendations which will influence how people are treated in the future and help to avoid the type of situation that Glenn faced. So thank so much for being here.

Ms Morton: Thank you for having me.

Proceedings suspended from 13:53 to 14:33
LOH, Associate Professor Richard, Consultant, Allergy/Clinical Immunology, Child and Adolescent Health Service

Evidence was taken via teleconference—

CHAIR: We'll start with the formalities. Do you have any comments to make on the capacity in which you appear?

Prof. Loh: I am appearing to the committee as the representative for the Child and Adolescent Health Service. I've also made a private submission to the committee.

CHAIR: I need to remind you that today's hearing is a formal proceeding of the parliament. The giving of false or misleading evidence is a serious matter. Your evidence today will be recorded by Hansard and attracts parliamentary privilege. Thank you for your submissions. I invite you to make a brief opening statement.

Prof. Loh: Thank you for the invitation to appear before the committee. I apologise for not attending in person, but I have a clinic today with a long waiting list that the committee has heard about. Rescheduling would result in my patients having to wait many months.

I am a paediatric clinical immunologist. I work predominantly in the public sector in the Perth Children's Hospital, the only tertiary hospital in WA, as well as the diagnostic laboratory. I also have one private clinic a week, so I have experience with some of the problems both in public as well as in private. I wear many hats, including past president of the Australasian Society of Clinical Immunology and Allergy—they are called ASCIA—and past co-chair of the National Allergy Strategy—I'll call that NAS. I'm a past board member of Allergy & Anaphylaxis Australia—I'll call that A&AA—and I'm also the past head of department of the Perth Children's Hospital. The chief executive of the Child and Adolescent Health Service, Dr Aresh Anwar, has also made a submission, and he has kindly asked if I could also represent CAHS to the committee.

Based on the evidence that's been received, the committee is well aware of the burden of allergic diseases on patients and their families in Australia. I've three issues that I would like to highlight. The first issue is clinical care standards for anaphylaxis. ASCIA, Allergy & Anaphylaxis Australia and NAS have led the world in the development of excellent resources for the management of allergic diseases, including anaphylaxis. Despite this, Australia has had an increase in deaths from anaphylaxis, which has been highlighted by the submission of Dr Mullins, that I've read. CAHS supports a national approach, with the development of clinical care standards for anaphylaxis to standardise clinical practice for all professionals across Australia. For the past few years, NAS has been unsuccessfully advocating for additional funding through the Australian Commission on Safety and Quality in Health Care to develop clinical care standards. In November, when I made the submission, the commission had just informed me that the development of these standards was not progressing. Since then, there has been a change of heart, and I believe the commission is now working with NAS to progress the development of these standards, which I believe are critical. Development of these clinical standards, I believe, is relatively easy, as a lot of the groundwork has been done. However, we must ensure that implementation is supported and a robust system is established to monitor and audit implementation.

The second issue is drug allergy. Many of the submissions have been around food allergy, but drug allergy is the single most important cause of fatal anaphylaxis in Australia. Patients with documented severe drug allergies have been given the drug in error in health settings in Australia. This has been published. The National Allergy Strategy was funded by the Australian government to scope clinical education and allergy documentation required to reduce drug allergy deaths in 2017. But since the submission of the report in 2017, nothing has progressed in terms of implementation of the recommendations of the scoping report. Antibiotics are a drug cluster often overlabelled as the cause of drug allergy, and delabelling is critical, as many patients who think that they're drug allergic are not, and they are prescribed antibiotics that are inappropriate. All patients with unverified penicillin allergy should undergo a diagnostic evaluation, and, at present, there has been very little progress in this area. The development and implementation of national delabelling guidelines for penicillin are essential.

The third and last issue is the shared care model for allergic diseases. The committee has heard a lot from the national allergy about shared care models, and the Australian government has funded a shared care scoping project. The final recommendations were submitted to the Australian government in December last year, and it's critical that this document doesn't sit on shelves like the drug allergy report. We need leadership and commitment at the highest levels of government—Commonwealth, state and territory—to progress and implement this shared-care model. Funding for health is not a bottomless pit. It's essential that we have the expertise of health economists, experts in public health and implementation evaluation specialists, plus it's about how we evaluate new shared-care models of delivering service. We must reduce bureaucracy and cost-shifting.
Development and implementation of shared-care models will take time, and in the interim we need to examine public hospital outpatient allergy funding and services, with a view to expanding access. To address this, we need to rapidly progress the non-admitted-care-costing study by the Independent Hospital Pricing Authority to ensure that it includes allergic diseases. And we need to implement the findings of this study.

I will stop there, because I believe I've been given three minutes. I'm happy to take questions.

**CHAIR:** Thank you, Professor Loh. It's always good to have a witness who follows the guidance in relation to opening statements! Of course, everyone's been doing that today! In your submission you talked about the waiting lists in WA—in particular, you indicated that waiting lists could range from 12 weeks to five years. A five-year wait seems to be extraordinary—presumably, that's after some type of triage process. I'm just wondering whether you could give us a feel for what people might be waiting five years for, and what circumstances they might be in?

**Prof. Loh:** There are some conditions that we deal with, like allergic rhinitis, which are not life-threatening, so patients often languish on waiting lists. When they get an appointment—sometimes two years later—and they don't attend the appointment because they've forgotten or they've had other issues, then they go back onto the waiting list after they're contacted and they're asked, 'Do you want to wait to see a doctor?' and they say yes. So that's why it has gone up to five years. Those are quite rare.

But if you have allergic rhinitis or hayfever, a two-year wait is not uncommon. At present, we are actually trying to make a decision on whether we actually see patients on this because it's such a long wait. The problem is that they have very limited avenues. They go to a GP and some of the GPs say, 'We don't have the skills to manage it.' So they go to see their GP and the GP writes back to us, saying, 'We want you to see this patient.' So the patients get bounced around, unfortunately, in this kind of system.

**CHAIR:** That leads me to my second question, which is related to that. With such long waiting lists in the public system, how much of the type of work that people are being referred to specialist care for could actually be managed primarily by GPs, with the right training? For example: is that an example of an allergic condition where a GP could be equipped to provide the type of management that the patient would need?

**Prof. Loh:** Allergic diseases affect up to 20 per cent of the Australian population. It is not a specialty condition when 20 per cent of the population is affected. I think that the majority should be managed by GPs and also by pediatricians. The problem with training—and it changes in various states—is that the only exposure that many GPs get for allergy is in the fifth year of medicine under the old system of six years of medicine. And if you are in the four-year graduate program, it's in your third year.

So in terms of training the people who come through my department, we train six, either residents or registrars, a year out of the 500 medical graduates who are coming through. That is the only training that they'll get. They will then be trained by GPs and by pediatricians. Some of them have really good skills, but some of them have been practising for 20, 30 or 40 years and allergy, 20 or 30 years ago, was very different from now. So we need to provide the teaching. We don't now have funding by the government but by the Perth Children's Hospital Foundation. We got funded for three years for a nurse practitioner and for a GP. In the hospital we had a three year wait for eczema, for instance, and that has been cut down to four months in the space of 12 to 18 months. If you provide good admin support and you provide the nurse practitioners and you provide GPs, we can actually demonstrate that this model can reduce costs and be quite efficient. We need to be much smarter in the way we deliver services. It's not just all allergy specialists.

**CHAIR:** My last question, arising from that, was that, whilst we are capable of making recommendations that might be pursued by state authorities, our primary interest as a committee is the role of the federal government. On issues like that, what do you see as being the role of the federal government when it comes to, for example, decisions that are being made within the state hospital system?

**Prof. Loh:** I believe leadership is required. I have been doing this for quite some time. Trying to get this on the agenda of AHMAC, the Australian Health Ministers' Advisory Council, where we have both Commonwealth and state and territory, COAG, so I think, if government at all levels said, 'This is really important and it's something that we believe needs to be managed,' then it actually lets people below them say, 'We need to deal with it.'

In terms of one specific area, when I looked at quite a number of submissions people were saying our patients are perhaps not as important as other things. One of the ways our patients get funded is based on something called a weighted activity unit. I mentioned this very briefly and I was hoping you would ask the question: how does the Independent Hospital Pricing Authority, which is more federally funded, assess how much funding the hospital should get for a patient getting an appendix removed versus a patient seeing our allergy specialists. But the
system, I believe, is really quite committed. If there is $10 million for patients with allergies, and you doubled the number of patients you see, you'll still get $10 million, but you'll get half the amount per patients. When I go to my bosses and say, 'We need some more funding,' they look at the weighted activity unit and all of that and basically say, 'Well, you're not bringing in more money,' despite the fact we might be seeing 50 per cent of patients. The smarter we get by making less complex patients go see GPs, we end up with very complex patients who still pay the same amount of money. It takes up two to three times the amount of time. The Independent Hospital Pricing Authority recognises it. They do know that cost funding for non-administered activity needs to be improved. They're doing the study, but, as far as I know, they're not looking at allergic diseases. Certainly, we put up our hand and said, 'We want to know and to help understand the costings,' but I don't think that they'll change it for any allergy department, either children or adults, in Australia. I may be incorrect, but, as far as I know, that has not progressed.

How do you ask for more funding to do challenges and all that? At present, all they see is this weighted activity unit. They are basically saying, 'We're not getting more money for this, so why should we fund you more for a nurse or for a GP or for whatever the heads of department are asking for.' That's a federal thing. I think this committee could ask the Independent Hospital Pricing Authority to give some understanding on funding, which may help us.

Dr FREELANDER: I'm just interested in some of the things that you have said. In your submission you mentioned that there were two paediatric food allergy anaphylaxis fatalities. What were they due to? What foods?

Prof. Loh: Can you believe, I have been head of the department in WA since 1993. I was hoping to step down without a single death, but we've had two deaths, none of which the coroner in WA has actually looked at. I strongly believe that all deaths should be referred to coroners, and I really believe that inquests should be held. If you look, I have been an expert witness at two coronial inquests. The outcomes from these inquests change what we do. By word of mouth, the first death was from milk allergy. It is very important that I don't compromise coronial investigations but this is in the newspaper. This child was known to be milk allergic but was given milk in a school. One has to understand then during an inquest how a child who is known to be allergic could be given a food that they are allergic to. But it also highlights that everybody is worried about peanuts and tree nuts but almost half the deaths I am aware of in Australia in children and young adults is due to milk. People need to understand that. How do you ban milk from schools and child care, especially child care? It is really important and you brought up this issue, which is something I am very passionate about. The fact is that we have had two deaths. My understanding of the second death is that the patient may have had anaphylaxis prior to the fatal anaphylaxis and was not referred. That one is from second-hand hearsay.

Dr FREELANDER: We have certainly had several in New South Wales including one that occurred in a hospital in a child that was known to be milk allergic but every case deserves a coronial investigation because they are all educative. What is your view on that?

Prof. Loh: I totally agree. If the committee could address that because Dr Mullins, who has looked at this, said there is a lot of misdiagnosis. There were asthma attacks that were not asthma but were allergy. If people look at all the submissions from me, it is a no-brainer. It is not actually food allergy; it is actually drug allergy. There are things that we can do now that actually save money by appropriate use of antimicrobials. We can save it in three to five years. With a lot of things that you talk about to prevent allergies, you might get benefits maybe 15 or 20 years later in terms of cost to the budget. But if we do appropriate management of drug allergy we can actually find money that perhaps we can use for other projects.

Dr FREELANDER: There has been a lot of evidence about the long delays for appointments in the multidisciplinary allergy clinics. What is your view about the use nurse practitioners to provide a triage type system?

Prof. Loh: In the eczema project that was funded by our foundation we use nurse practitioners. I think one of the issues which may not have been touched on by the committee is actually defining scope of practice. Is it the scope of practice of nurse practitioners? Is it the scope of practice of GPs who take on additional training or paediatricians? It is actually to work out the training that is required and the scope of practice. We need to address this. It means working with the college of GPs, the college of physicians, nurse practitioners and we need to not protect ourselves. I am saying that if we can do this then perhaps we don't need to do so much in private or whatever. It is really important. The national allergy strategy, you are right to put the patient and their families at the centre of everything we do. So if we look at the scope of practice and training—what can be done, how do we maintain the scope, what kinds of training and all that, I think that is something. The model of care talks about it and I think we need to do it; it has to be done. I know Connie has presented for the University of Western Sydney. What is the scope of practice for GPS there?
Dr FREELANDER: Yes, she has.

Prof. Loh: Patients should understand so they can say yes. Allergists like myself with 25 of experience probably have more experience, but is it better to wait two years to see me or somebody else in six weeks? I really think that probably six weeks, to at least deal with the most urgent issues for the patient.

Dr FREELANDER: Connie is very big on that. Thank you very much.

Prof. Loh: My pleasure.

CHAIR: That is the end of our questions. Thank you for your submission and for your advocacy for this inquiry predating its commencement. We will send you a Hansard transcript of today’s proceedings and if there are any additional matters you would like to raise with the committee once you have seen that transcript, please feel free to do so. Thank you for your time.

Committee adjourned at 14:55