
Allergy Care Focus Groups: Full Report

The following focus groups were held on 25/10/2010 at the Royal College of Paediatrics and Child Health offices in central London, by Bridget Hopwood and Amy Tallett:

Group 1: 10.15am-11am

- 1) 11 year old male with asthma, rhinitis and eczema
- 2) 9 year old female with asthma, rhinitis, eczema, food allergies, anaphylaxis plus other (latex, pets, dust)
- 3) 8 year old female with asthma, rhinitis and food allergies
- 4) 8 year old male with asthma, rhinitis, eczema, food allergies and anaphylaxis
- 5) 10 year old male with asthma and food allergies
- 6) 11 year old female with eczema and food allergies

Group 2: 11.10am-12 noon

- 1) Female parent of 11 year old (parent of participant 1 in group 1)
- 2) Female parent of 8 year old (parent of participant 4 in group 1)
- 3) Female parent of 8 year old (parent of participant 3 in group 1)
- 4) Female parent of 9 year old (parent of participant 2 in group 1)
- 5) Female parent of 15 year old (parent of participant 2 in group 3)
- 6) Female parent of 15 year old boy (parent of participant 1 in group 3)
- 7) Female parent of 10 year old boy (parent of participant 5 in group 1)

Group 3: 12.20pm-1.00pm

- 1) 15 year old male with asthma, rhinitis, eczema and food allergies
- 2) 15 year old female with rhinitis, eczema, food allergies and anaphylaxis
- 3) 16 year old female with asthma, rhinitis, urticaria and angiodema
- 4) 21 year old female with food allergies, anaphylaxis and mastocytosis

Main Themes

- 1) Support
- 2) Confirming the diagnosis
- 3) Information about treatment
- 4) Seeing health professionals

1) Support

Support was a theme that arose across the focus groups, in terms of support groups, support from the child's school and support from friends/family and other people with allergies.

Support from others:

Younger children themselves didn't really know many other people with allergies and sometimes felt that friends treat them differently and/or don't understand about the allergy they have.

Support at school

In terms of school, children felt that it varied between teachers whether or not they knew about their allergy or not. Although the school often had access to the child's treatment, the teachers would not necessarily know what to do if the child had a reaction.

"INSERT QUOTES"

Action: As a result of the concern about lack of support, a section of the questionnaire was dedicated to this ('Lifestyle Support'), covering questions on support at school, contact numbers, information on support groups and psychological support, along with an open-ended question asking what further support is needed. Children with a personal management plan were also asked whether their school had been told about this.

2) Confirming the diagnosis

The diagnosis of the child's allergy is not always confirmed, but children / parents just know that it exists due to the symptoms/reactions that the child has, for example to certain foods.

Tests are not always done to confirm the diagnosis. Instead, children/parents are often just advised to avoid the allergen.

Even when tests are done to see if the child is still allergic, these cannot be 100% certain so child is still advised to avoid the allergen.

3) Information about treatment

Although children felt they had enough information about their allergy itself, many children and parents felt that they did not have enough information about the allergy treatment. For example in some cases, the child had a reaction and did not use the relevant treatment (Epi Pen), but were advised afterwards by the doctor that they should have used it.

Children are not always told how to use treatment directly, sometimes their parent is told and then it becomes the parents responsibility to explain this to their child and write down instructions for them to carry with the treatment. This applied to both Epi Pen and inhalers.

Where treatment was not effective, some children are not told about alternative options:

- "...and they always give it to me but it never works so we ask for something else. But when I get the same thing it never works - but they don't really give me anything different"
- "[professionals should] give more different creams or different things for the person that has already tried it but it doesn't work"

Some treatment can be quite complicated, which demonstrates the importance of receiving enough information:

- "You have to keep the medications up on a regular basis, the creams, the lotions, potions and it has to be quite a rigid regime"

4) Seeing Health Professionals

Children received various types of care for their allergy, including GP appointments and check-ups and urgent care e.g. Accident & Emergency hospital departments. Children reported seeing hospital doctors and ENT doctors during hospital appointments, paediatric consultants during A & E visits, GP's, nurses in hospital.

Therefore any allergy healthcare questionnaire should cover as many of these aspects of allergy care as possible.

The following were important to children when seeing a healthcare professional about their allergy:

- Communication - children like to be talked to in a child-friendly manner, and like things to be explained and to know what is happening:
 - "she explains everything very well - in like a child way so that I can understand it for myself"
 - "I would want someone to explain it... I wouldn't like to just have it [injection] and not know what I am doing, I just like to know... because I had a blood test the other day and I like to be told... because the first time I had it I wasn't told and it really hurt me".

- Knowledge about medical history – children do not like to repeat information about their allergy every time they see a healthcare professional:
 - “he knows all my allergies and on his system all my allergies come up”
- Being listened to:
 - “There was this receptionist at the front desk and when my mum wants to ask if she has any prescriptions she asks her but she doesn’t listen and carries on using the computer and not listening”.
 - “I remember someone – I forgot her name – she was a receptionist in the hospital, I think. Every time my mum went in to ask her for something, she wouldn’t listen”

Action: a section of the questionnaire was dedicated to emergency care and another to allergy appointments. Within these sections, questions ask about communication with healthcare professionals and whether healthcare professionals knew enough about the child’s medical/family history.

Group 2 - Parents: Main Findings

Words that come to mind when parents think of their child’s allergy healthcare

- **“Discrimination”**
 - in terms of getting into school (see schooling section below)
 - extra-curricular activities: “now I am in this position where she is facing kind of discrimination with – she doesn’t fit into like the extended school services and things – holidays – they blatantly say No because they don’t have anyone Epi Pen trained. So again they said that I have to apply for funding”.
 - Funding and help: “so if I went down the other route via a social worker and everything to get her – for medical needs – she comes under Complex Medical Health Needs – she doesn’t fit into a criteria because she is not severely disabled – so it is border line”.
- **“Anxious”**
- **“Unacceptable treatment”**
- **“I think it has improved”**
- **“Good care plan”**

Diagnosis and Referral:

- There was a general feeling that after initial diagnosis, parents were left in the lurch and not given enough information about their child's diagnosis.
- In situations where the child was referred, there was often a long gap between initial appointment/finding out about the allergy and seeing a specialist, which appears to be due to lack of communication between healthcare professionals:
 - o "we went to A & E and they treated her with steroids and got it under control... they said - We will have to refer her for allergy testing... I said OK – so I went to the front desk and did all that. Two weeks went by and I heard absolutely nothing so I then went to my GP who had heard nothing, no report or anything from the hospital. So they said 'We will have to refer you'. So they referred us to St Mary's but it was four months from when she had the reaction".
 - o "he was going into anaphylactic shock but of course I didn't actually know. So we did see an emergency doctor...and then we went home – after two hours – and that was it. It was only because I had my other son and I had gone in for a check up and I had to speak to the GP and he mentioned it – and she said 'What is happening now?' and I said – about six weeks later 'I don't know'... She said "Well I will refer you" and I think this originally happened the first couple of days of May – so I think by the time I had seen her – you are talking well into June – and we didn't see anyone until November"
 - o "had an allergic reaction to strawberries for the first time in July and I went along to my GP to get her referred to find out whether she is actually allergic to the strawberries or whether it was something else but we have been told that we have to wait until April for an appointment. So it is quite a long time".
 - o "what we find is when she [GP] refers us it is quite a long time until you actually get to that point of getting the information or the care that we need".
 - o "the worst thing for us was that initial – non referral – nothing happening – being completely left... and I have been alarmed that... we could have killed him by accident".
 - o "My son has eczema and asthma but he didn't refer me for allergy tests. I asked him a couple of times before I realised he had an allergy".
- Children often leave urgent care admissions without an Epi Pen after a severe reaction: "they did more testing and they tested kiwi fruit and they said 'Yes she has got an anaphylactic reaction' – but they were horrified that we had been allowed to leave the hospital back in March without an Epi Pen. So four months we had been walking around"
- A lot of the parents would like more information on their child's condition after being told about it:
 - o "because you don't know anything about potential allergies – you avoid the nuts but you think – they contain nut traces – what's all that about – oh they'll

be fine. You wouldn't do that if you actually really had been given a leaflet at the early stages saying "We don't know, we might suspect, it might be prudent to follow this line"

- "you educate yourself and you learn to work with the system"
- "They gave me an Epi Pen and that was it – I went home. And I was devastated, mortified but I would have appreciated this information. I actually went on the Web and searched – I was desperate for information, desperate for support, does anyone know about this? Was there a support group where I can go to?"
- "in terms of knowledge, I didn't have a clue... it was not enough information – nothing – in fact no information. Then I went to – then I discovered the Anaphylaxis Campaign – luckily someone – I was calling everyone possible in the phone book, on the net and I got in touch with "Contact a Family" who have been amazing to this day."

Repeat visits to healthcare professionals:

- "With my daughter when she had eczema it just always kept getting infected. So the difficulty was trying to get rid of the infection so as well as having the creams and the stuff to go into the bath it was also about going back to the doctors and courses of anti biotics to get rid of the infection as well".

Problems with Schooling and other times where parent is not present (e.g. social activities)

- Schools/teachers not helpful with child's allergy and may not intervene with an allergic reaction.
 - one particular parent took their child out of school for this reason and is being home tutored: "they [schools] don't have to have that care in place. And so I became quite fearful that she could be at school and have an allergic reaction – I hope someone would take responsibility for it but they didn't have to unless someone volunteers... They are not obliged to give the injections or put a plaster on nowadays – they do not have to... she just wants to be there at school with her friends – she wants to be a normal 8 year old". "Obviously for me a big issue since [child] was four has been her education and it has been a real struggle, particularly over the last year – [child] has now got six tutors that come home because we just don't know what to do with her in terms of her education"
 - A nursery would not take one child on until they were 5 due to their allergies and then was not welcomed by another school: "they said Well we have to apply for funding and if we don't get the funding, then by law we don't have to take her until she is five... the other school actually gave me a place... the

health visitor went behind my back, phoned this new school up and said Do you know what you are taking on?... the nursery teacher was absolutely horrible – she didn't even want to know me – she turned her back – I felt sick – I thought I don't want my child to come here”.

- Schools and nurseries not always trained in helping child: “nursery didn't really have... the care strategies weren't set in place like they are in schools. So when he went to nursery there was – we tried to get them Epi Pen training – they were happy to do it but when we went through the GPs and the Health Visitors... there was no funding at that time for nursery staff to be trained”. “There are not enough medical professionals to give Epi Pen training”.
- Some teachers had training for medication: “Well I work in a school – in a normal state school – but our staff have all had Epi Pen training”.
- Similar problems arise for events outside of school: “my son went to Beavers and the woman that ran it... couldn't deal with his allergy and wasn't interested”.
- There was an understanding that teachers/event leaders may not always be able to intervene and give medication, but agreed that problems were with communication. One parent experience of her child with a nut allergy attending Cubs: “My husband took him one week and found they were doing bird feeders – of course he was only able to stay fifteen minutes... I said He needs to come home, are they prepared to not do it? But she wasn't prepared to. It was only when she moved into a different role and somebody else came in who had been there for a while and who was open and communicated when they were doing food or bird feeder things in advance. And that is actually all that you need – you don't need – you just need a bit of communication but she actually wasn't interested and never has been”.
- The general consensus was that it is the parents' responsibility to communicate with their child's school about their allergy as opposed to the healthcare professionals

Treatment

- Parents tend to receive relevant training for their child's allergy treatment: “I have been, as you probably all have been, on plenty of Epi Pen training courses and you try and keep up-to-date”
- Some medication can be expensive: “you know they have to wear the medical bracelets – they cost a fortune”.
- Doctors often explain treatment to the parent who then relays the information to their child: “Yes they explained to me and then I taught him how to use it and so after a while he got used to it”. → however, some agreed that it is important to speak directly to the child as well: “they could talk to the children as well as the parent – because the child should know – because the child is not with you all the time – they are in school or maybe with family or relatives so they have to know their conditions and take responsibility as well”.

- Generally, parents were happy with the treatment/medication that child had for their allergy

Tests

- Regular tests to identify existing and new allergens:
 - o "They did a skin prick – well – she wasn't allowed to have the skin prick test until she was 4 because they say it is too young at that age – so she had it at 4. And she has basically had them every year and she is now 14. But a few more things have come up – six types of grasses – 3 types of trees".
 - o "But every year they give her the skin prick test and the check for airways"
 - o "...and is tested every year – skin prick test – and they said if she wanted to try anything new – like she wanted to try some chicken and rich tea biscuits – I brought a bit in and they took a bit and tested her and she was OK"
- Others did not have regular tests – only when necessary:
 - o "if I went in and said We think there is something new or I have a problem they would test my son – but there is no – he hasn't been tested since he was five" [he is now 11].

Healthcare staff not knowing enough about child's allergy

- Lack of information has caused doctors to prescribe the wrong treatment
 - o "my GP actually prescribed my daughter a vitamin supplement... with soya in it. And she had a reaction the same night – and when I got home I peeled back the label and as soon as she took it, within five minutes, tickly throat, wheezing. And I came down, pulled the label back and I had my trust in this doctor, so I have lost my trust".
 - o "my daughter developed a rash all over her body and I was quite worried – it was like red/purple dots – but no itching, no temperature, nothing else. So I took her to the GP and they said... 'Here is the cream just try it anyway' and I said 'Are you sure because last time she reacted?' So just to be on the safe side, I kept her home, used this cream and she reacted violently to it within hours. Her body was burning, it was all red and inflame".
- A concern about A & E staff not knowing enough:
 - o "The doctor at A & E... she was going through the list of allergies – I have told her it is Latex – so what does she go and do she goes and grabs a pair of latex gloves to examine my daughter and I had to say 'Stop you have to wear latex free gloves'. And she blank face looked at me – she didn't have a clue".
 - o "A & E are front line staff so there is a massive difference between the day to day management – the experts. A & E don't have a clue and they are a

disaster... but that is quite worrying because – I don't know if frontline staff is the correct word – but they are your first port of call and the A & E Department should be latex free. Say if an anaphylactic patient went in unconscious, they should automatically and routinely use latex free gloves”.

- “in A & E when someone goes in with the allergy... they need to take it seriously and then when they are treating, they need to make sure they don't cause further anaphylaxis by using the wrong stuff or misdiagnosing. And that – I have just lost my faith”.

Check Ups

- Opinions varied, some had regular appointments and were happy, some only had when they felt they needed, and others needed more: “I would like to have check ups at least once a year and we don't have”.

Communication with children

- Parents want professionals to talk to their child as well as them. “the child should know – because the child is not with you all the time... so they have to know their conditions and take responsibility as well”.

Positive aspects of child's healthcare

- Getting enough information from specialists “I have had a good allergy specialist, dietician who has been telling me what we can get on prescription and if I have asked they have told me what I wanted to know”
- Support groups:
 - “The best parts have been – I have a good relationship with my GP – the Anaphylaxis Campaign – I don't think we would have coped with any of it because I agree there is no clear route of where you are going”.
 - “But the best thing for us has been the Anaphylaxis Campaign, the information we have had... the parent workshops that they have done – I am very keen for my son to attend – he is now falling into the age bracket where he can attend – I think they call it a Family Workshop... Apart from the Anaphylaxis Campaign, I don't see any guidance”
- GP/specialists:
 - “I have a fantastic relationship with my GP – absolutely brilliant... The GP has been absolutely fantastic but of course she is only one part of the link in the care.”

- “For me a good thing has been that I have been lucky that I have had a good allergy specialist, dietician who has been telling me what we can get on prescription and if I have asked they have told me what I wanted to know”.
- Child being treated appropriately for their age:
 - “once she got diagnosed with the anaphylaxis... he really kind of took her as a whole person... getting her through the summer and she has skin reactions, which for a fourteen/fifteen year old, she is really, really conscious of. So he would look at kind of stuff that she could be cleansing herself with, moisturisers – so it was a whole package and that has been fantastic. He has kind of looked beyond... because she is doing her GCSE’s – where we usually see him in July, next year he is seeing her in April to make sure that everything is OK before she does her GCSE’s”.

Negative aspects of child’s healthcare

- The uncertainty that parents felt before the diagnosis is confirmed:
 - “I would say the worst bit was before [child] was actually diagnosed with the anaphylaxis because we were dealing with allergies to lots of different things... there was no, one clear line of treatment. You know – you go to a GP – try this, try that – so we were very much just going on recommendations from people and just trying different things and there was no one clear route”.

Group 3 – Older Children: Main Findings

Diagnosis – lack of information/treatment and length of time to be referred for testing

- Some children were not given enough information or treatment following their initial reaction/diagnosis:
 - “I went to A & E and I sat there for ages with like a cold flannel on my face and then they gave me steroids and anti histamines and then I just went home... They didn’t send me home with an EpiPen or anything”.
 - “I think my mum thought it was a bad reaction but I didn’t know I’d had anaphylaxia and then I think about a year or six months after – I don’t know how long it was but it was a long time after – I went to [Hospital Allergy Department] and got the skin prick tests done... and he said ‘Yes you have got Anaphylaxia’ and I was like ‘Sorry I don’t know what that means’... and then they gave me an Epi Pen and showed me how to use it and that was it”.
 - “At the beginning when he said ‘Oh you have got Anaphylaxia’ I was like – I didn’t know – I had heard the word before but I didn’t know what it was and

I didn't know how serious it could be. And then he sort of explained to me. My mum knew a bit about it".

- "we went to the hospital and then the doctor just said to me 'Well we think you have got an allergy' and they gave me anti histamines and steroids and kept me there for a few hours. The swelling went down a bit and then they just gave me a prescription and handed me an Epi Pen and told me to go home. But I didn't know what an Epi Pen was for or anything... I was never trained until two weeks ago".
- "I know how to use it [EpiPen] now. When I went to [Hospital] I was taught how to use it".
- "Well I know nothing about urticaria and angiodema... my mum and dad don't even know much either. They never gave me a booklet or told me where I could find out anything about it - they just told me what I had and gave me tablets and gave me my Epi Pen and told me to go home".
- 2When I was first diagnosed, it was a bit iffy - they were like 'You could have it and it is a bit rare' and gave us this name. We searched on the Internet and I was lucky to come across an online support group".

Information

- Older children were interested in their allergy and wanted more information about the causes:
 - "Yes [I would like more information] - not because I find it difficult living with it - but just because I thought it might be a bit interesting and find out what it actually is".
 - "I am quite confident with my allergies but I would like to know more about other ways of controlling it and how to reduce the risks. The biological side of it and how the allergy occurs".
 - "if I wanted to learn how the - like why does the allergy occur... you understand and probably take it a bit more seriously... if you know what is happening to your body - I think when I was first diagnosed I would have taken my Epi Pen with me because I would have understood that using that Epi Pen is going to stop that from doing this. Yes and what it does in the body - that would be quite useful for teenagers onwards. I think if you were ten and under I don't think you would understand but I think secondary school onwards I think you would take it more seriously".

Time taken to refer

- "I had loads of other symptoms and kept going to the hospital and we kept saying that whenever I ate bread it burned my throat and that went on for about four months. Then we saw a dietician when I was an inpatient"

School

- The older girl in the group mentioned that she found things difficult at school due to her allergy:
 - o "I have got used to it – I have had it since I was fourteen. When you are fourteen/fifteen you change your friends anyway – so I kind of learned who my friends were – because I couldn't go to school. Now at Uni it is fine – everyone understands and it is much better actually than being at school - I struggled at school – it is better being at Uni".
- Some children were not sure whether their school knew about their allergy:
 - o "I don't know if they know that I have allergies".
- Children were uncertain whether or not their school would be able to deal with their allergic reactions:
 - o "I don't know if any of them [teachers] are trained in allergies because – I know there is no one in my year that has like a bad allergy or anything. There are probably loads of people that have nut allergies but I don't think they know – I don't know if they are trained – first aid trained – but I don't know if they know how to use an Epi Pen".
 - o "most of my teachers – they are just like "This girl has got an Epi Pen" and they are like "Well what do I do if she has another attack?"
 - o "Well at college, they knew about it [the allergy] but they said that they wouldn't be allowed to use my Epi Pen – like they wouldn't be covered – and we had a big meeting and mum – she is quite blatant – and she said "Well you would be prepared to let her die if you are not going to give her the Epi Pen?" and they said "Yes". I have got dyslexia as well, so I had a note taker – and she was really good – and learned to use the Epi Pen".
 - o "I generally can do it by myself [EpiPen] – but then at Uni – they know but because you are more independent – I had a reaction in his lecture and he just carried on with the lecture. All my friends were shocked... I think he [lecturer] doesn't understand anaphylaxis"

Using treatment

- Children did not always seem clear on how or when to use their treatment or they have had to learn themselves:
 - o "Yes I have learned – like the hard way – once – it was the first time I was on my own and I didn't want to use it [EpiPen] so I was walking around and I got really bad and ended up in HDU because I didn't use it quick enough. So now I have learned to recognise the smallest symptoms and now know when to use it".
 - o "Then my first anaphylaxis was... I basically got temporarily paralysed from it because I didn't use my Epi Pen and I didn't take it with me because I had never had one before... basically my body was trying to save it's organs that basically you don't need your legs and that is basically why I have got a

stick as well because – it was like four years now – but my left leg – the feeling is still not all back”.

- “I was never taught [how to use EpiPen] – [Name] – she came to my house and gave me a train up... she was the person that taught me so I am trusting that it was right”. (this was a neighbour, not a healthcare professional).
- In contrast, some children were confident about using their treatment:
 - “I have had the skin prick test... I have never had to use my EpiPen. I rarely get allergies. When I had my skin prick test they taught me [how to use the EpiPen]”.

Support Groups

- Children felt like they wanted to talk to others about their allergy and have access to support groups:
 - “Yes – I think it would be easier – it is just like – it is not just you having your allergy – I have got quite a weird one, so kiwi and parsnips, I don’t anyone that has that but it is just nice to talk to other people and see what they have got and how they deal with it”.

Lack of knowledge of allergy from professionals

- Some children said that healthcare professionals did not recognise their allergy:
 - “Well I was taken to hospital and they thought I was drunk. Then my mum came and gave me anti histamines, like loads of them and I kept blacking out, but I never had the Epi Pen... they thought it was a stroke at first as well – I had an MRI. I saw my consultant in [city name] and she was like ‘It is Anaphylaxis and you really need to know what to do next time and recognise it’.”
 - “There was an A & E doctor that I saw and he basically said ‘There is no such thing as mastocytosis’ that my Anaphylaxis with a panic attack and he wouldn’t give me the adrenalin and my mum had to come and give it to me. And I have seen him a few times and he is awful – I am just glad that I don’t live in [city name] any more... basically he didn’t recognise that anaphylaxis isn’t just facial swelling, it can happen further down and you can’t see it but you get paler and your blood pressure goes low – but he didn’t”.
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Positive aspects of allergy care:

- “My GP... she was the first person that I saw and she was really good. She got my referral done really quickly... she was really helpful because she didn’t know what was wrong with me that is why she referred me but she was really helpful”

- I remember the Professor when he was talking about the ways that I can improve the conditions”
- “The consultant allergist that I still see in [city name] – she just talks to me like a normal person, she doesn’t talk down to me and I think because she is a consultant allergist she understands it... and she is willing to look further and I think that is like a good doctor – she won’t just do her work and go home – she will do her work, go home and look at more things that could be useful”.

Negative aspects of having an allergy

- Some children felt **self conscious**:
 - o “It is how it affects your appearance so say if you have got some – I get rashes across my face and sometimes they are quite big... It makes you feel self-conscious”.
 - o “my skin always gets loads of rashes when the weather changes – so when it goes from – like the other week when it was quite warm and then it suddenly went cold – I get horrible rashes”
- Some children felt **isolated** due to their allergy as it restricted what they could and could not do with friends:
 - o “At one time when it was an airborne allergy, it was really difficult because I couldn’t go out clubbing with all my friends, they would always have to come to mine. Even at Uni I couldn’t go into the canteen, so the whole group would go into the canteen for their break – I just had my friend, Sophie, who would stick with me – we just had to sit in Reception – but if Sophie wasn’t there I just had to sit on my own”.
 - o “It is a bit upsetting because everyone else is going [out] and you have to sit at home and just be bored by yourself, especially in the summer when everyone goes to the park and has like a water fight and you are just sitting at home”.
 - o “at Uni... I am right by the door [in lectures] – he always puts me by the door in case something happens”

When asked what could be made better

- “Training in the Epi Pen”.