Let's not be rash

'Parental Experience of Allergy Diagnosis in Children, A Joint Report by Stockport Allergy Mamas and Healthwatch Stockport"

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Contents

1. Executive Summary

What do we think when we talk about allergies? We mostly get asked if we are allergic to anything when we go to the doctors or when we receive vaccines or medical interventions. We might quote the case of a child at school who has a nut allergy and so nut based products were banned.

I suspect that when we talk about food allergies, unless you or a close family member or friend has one, it is difficult to quantify what impact it can have on you and your family's life.

When Stockport Allergy Mamas came to Healthwatch Stockport and told us about the work they were doing, a whole big conversation ensued about allergies. Most notably one of our own members of staff was saddened to hear that support for families does not seem to have improved over the last 20 years, as she went through similar experiences with her daughter [now in her 20's] to those of families today with children who have an allergy.

Although Stockport Allergy Mamas carried out the work around gathering the views before approaching Healthwatch Stockport to support presenting it to commissioners it really has been a joint effort to amplify the voices of people who may otherwise be ignored or not taken seriously.

The UK experiences some of the highest prevalence rates of allergies in the world and prescribed treatments for allergy care accounts for around 10% of a GP's prescribing budget [equating to around £900 million per year]. Food allergies could affect up 23,500 children in Stockport alone. This is staggering and prevalence has been increasing three-fold over the last 20-30 years, for those with severe reactions, hospital admissions have also risen in this time.

Yet, from listening to the experiences of families with children who have allergies, they feel unsupported and let down by services. They talk about being treated as neurotic and experience health professionals making assumptions about them as parents.

They spoke about their difficulties in accessing specialist help and delays in referrals as well as referrals not being completed.

More worryingly, 12 of the 17 participants who took part in this small study had been diagnosed formally with depression. All quoting the process of finding out more about their children's allergies and seeking support had impacted their mental health.

We hope that by raising awareness of the experiences of these families, we can work with health services to improve support, referral processes and the empathy shown to families at a time when they need it most.

Jade Mitchell Stockport Allergy Mamas

Maria Kildunne Chief Officer Healthwatch Stockport

2. Introduction

The Stockport Allergy Mamas group was set up by two local mums who found support in each other when struggling to navigate the world of having a child with allergies. They found there was no other specific support for parents of children with allergies in Stockport.

One of the main aims of the Stockport Allergy Mamas group is to ensure that all those parents who suspect their child has allergies or are displaying symptoms of allergies are given the same advice and resources by health professionals.

Whilst the group focuses upon mums, they do recognise that their child's condition impacts the whole family and, in the future, hope to set up a group for dad's. Due to the current Covid-19 pandemic, the supported offered by Stockport Mama's is currently via WhatsApp and Zoom, however in the coming months it is hoped this will move to face to face meetings.

Reasons for the Study

Members of the group started to notice patterns in the discussions happening within the group. The mums discussed the huge impact the journey to diagnosis was having on their maternal mental health and general wellbeing. These discussions also highlighted that GP's seemed to treat patients differently.

Group members wanted to see if any patterns could be identified in the approach GPs took and the affect this had on the mental wellbeing of the mum.

Based on these discussions the Stockport Allergy Mamas, they decided to produce and conduct a survey amongst its members, to explore the experiences of mums within their group.

The Group decided they wanted to work with Healthwatch Stockport to help them highlight the challenges faced by them to primary care commissioners and providers.

The Stockport Allergy Mamas group hopes that the findings provided from these experiences will:

Be used by Healthwatch Stockport to:

- Feedback to primary care and other health care professionals to help ensure parents are not dismissed as 'first time parents' or that babies are suffering with 'colic'.

- Help GPs and other health care professionals to understand that not having an empathetic approach can heavily impact maternal mental health and obviously the impact on the child when parents are dismissed.
- Help GPs/primary care professionals to identify symptoms of allergies much faster in children.
- Ensure parents will be given consistent, high quality advice and resources, to assist them until their child's diagnosis.
- Help develop a more efficient diagnosis pathway for any parents who suspect their child may have an allergy.

Healthwatch Stockport

Healthwatch Stockport is an independent health and social champion created to gather and represent the views of the public. We have three broad areas of work:

Inform. We provide information about health and social care support and services that works for you, helping you stay well. Our Information & Signposting service runs 5 days a week and we take enquires about health and social care related services and help to signpost people in the right direction – we can refer people who want to make a complaint about NHS Services to our partners – Stockport Advocacy who can support anyone throughout the process.

Involve. We gather your views and ensure you are listened to about what works well and what could be improved. We identify trends and themes and we use it as evidence to support our influence. Healthwatch Stockport is a member led organisation, we encourage as many people as possible to sign up as Healthwatch members so that everyone has the chance to be involved in our work.

Influence. Working with those that run services to ensure i**mprovements are made because of what you said**. We use feedback to work with commissioners to make services work for you.

3. Background

NICE Guidance

In February 2011 the National Institute for Health and Care Excellence (NICE) produced guidelines entitled 'Food allergy in children and young people - Diagnosis and assessment of food allergy in children and young people in primary care and community settings' these set out recommendations on how to consider the possibility of food allergy in children and young people, the diagnosis pathway and how to provide information and support to the child or young person and their parent or carer. The guidelines also include information around referral to secondary or specialist care

NICE [National Institute for Health and Care Excellence] - NICE's role is to improve outcomes for people using the NHS and other public health and social care services. They do this by: Producing evidence-based guidance and advice for health, public health and social care practitioners

British Journal General Practitioners (BJGP)

The paragraphs below were taken from an article that appeared in the BJGP in 2016:

Inconsistencies in the management of food allergy prompted the commissioning of projects such as the National Institute for Health and Care Excellence (NICE) clinical guideline on the diagnosis and assessment of food allergy in the community[1] and in 2014 the NICE Clinical Knowledge Summary looking specifically at the management of milk allergy.[3]

It has been shown that GPs' knowledge of these guidelines is poor. Inconsistencies remain in the management of milk allergy, with a particularly lengthy time period and multiple consultations before diagnosis.[4]

Allergy UK is a national charity that provides information about food allergy and spotting symptoms in children, they also provide free Factsheets to help guide parents around weaning and immunisations and a food diary template.

Allergy UK have published the facts below on prevalence of food allergy in the UK:

- The UK has some of the highest prevalence rates of allergic conditions in the world, with over 20% of the population affected by one or more allergic disorder. (M. L. Levy, 2004)

- A staggering 44% of British adults now suffer from at least one allergy and the number of sufferers is on the rise, growing by around 2 million between 2008 and 2009 alone. Almost half (48%) of sufferers have more than one allergy – that is around 10 million people (Foods Matter, 2010)

- The least likely to suffer from allergies are pensioners – with a 30% allergy rate among this group whereas women and younger adults (under 35) are the most likely to claim an allergy- around 50% (Foods Matter, 2010)

- In the 20 years to 2012 there was a 615% increase in the rate of hospital admissions for anaphylaxis in the UK (Turner PJ, 2015)

- The percentage of children diagnosed with allergic rhinitis and eczema have both trebled over the last 30 years (Gupta R, 2007)

- Between March 2013 and February 2014 there were a total of 20,318 finished admission episodes4 (FAEs) with a primary diagnosis of an allergy. This represents a 7.7% increase from 18,862 for the previous 12 months. (HSCIC, 2014)

- In the same year, 19.2% of emergency admissions were for anaphylactic reactions and 19.2% were for ‘Other’ allergic reactions. The lowest number of emergency admissions was for allergic rhinitis (1.0%). (HSCIC, 2014)

- In the UK, allergic diseases across all ages costs the NHS an estimated £900 million a year, mostly through prescribed treatments in primary care, representing 10% of the GP prescribing budget. (Venter, 2009)

- Almost a third of allergy sufferers have had to change their lifestyles to reduce their allergic reactions. Actions range from keeping their home extra clean (11%) to using special bedding (11%) (Foods Matter, 2010)

4. Method

To gather more in-depth information from group members, a survey [see appendix i] was conducted within the Stockport Allergy Mamas group network. Seventeen responses were received.

It was explained to participants at the beginning that the aim of the study was to help improve the allergy diagnosis pathway of children/babies with allergies. There was a section in the survey that stated the purpose of the research and asked participants to only continue if they consented to the sharing of the information.

As no personal or sensitive information was collected consent forms were not used, instead implied consent was used. This was checked via UK Data Service.

As no actual service was named by participants in the survey, no approach was made to any individual health professional or service. Stockport Allergy Mamas hope that by approaching Healthwatch Stockport they can help to facilitate a coordinated approach to involve all professionals.

The survey was created and conducted independently by Stockport Allergy Mamas, Healthwatch Stockport supported the group to present the findings and recommendations identified within this report to primary care providers and commissioners.

5. Key Findings

Below is a summary of the key findings received from the seventeen respondents to the survey conducted by the Stockport Allergy Mamas group.

Type of allergies
Of the seventeen families who took part in the survey, fifteen families had one child and two of the families had 2 children, where both children suffered with food allergies.

Each of the seventeen family's children suffered with food allergies, although these have not been broken down into types of food

Age of the children when parents first had concerns about their child's symptoms
Parents of the seventeen children included in this report had concerns about their child's health before they had reached the age of one.

Age of child when concerns first raised

2 x	Birth
3 x	Within one week
6 x	Two weeks – six weeks old
6 x	Two months – seven months old
1 x	One year old

Age of child when they received a diagnosis

9 x under six months old
6 x under twelve months old
3 x under eighteen months old

Tracking symptoms and advice from the GP on initial visit on suspecting something was wrong
Of the 17 parents who responded to the survey, eleven were given no advice around tracking symptoms, even though one of these mums suffered with allergies herself, took photos of all of her baby's reactions as evidence and made a note of what she thought had caused each reaction.

Some mums described having fantastic health professionals that advised them to make food journals and note down symptoms, however this was only a small number of the mums.

A&E attendance and hospital admission prior to diagnosis?

Over half of the families responded that their child did not require a hospital admission.

Of the children that did visit A&E, one was given adrenaline in the back of an ambulance at 7 months old and was blue-lighted into hospital.

Another child following NHS 111 advice attended A&E at 6 months due to loss of blood in bowels and having 40 bowel movements in a day.

Effects on mental health

Fifteen of the seventeen mums responded that their mental health had been affected during their child's journey to diagnosis. Many of these mums reported feeling anxious, stressed, scared, and depressed. Many of the mums highlighted they felt they were 'not being listened to' by health professionals but were being thought of as neurotic, with one mum quoting she was made to feel she was 'making it up'

Twelve of these mums went on to be formally diagnosed with postnatal depression.

Several the mums went on to explain how utterly exhausted they felt whilst trying to cope with their child's condition and how this went on to affect the family as a whole. One mum shared that her mental health has suffered because her relationship with food has been affected in that she now displays signs of bulimia/binge eating disorder

Concerns during the journey to allergy diagnosis

Many of the parents talked about the numerous visits to their GP or health professional with their concerns regarding several symptoms, all relating to their child's allergy.

There was general concern that GPs and some healthcare professionals seemed to have little familiarity with *IgE allergies. This led to delays in referrals to a specialist, in clear decision-making processes and in faster diagnoses.

**IgE-mediated food allergies cause your child's immune system to react abnormally when exposed to one or more specific foods such as milk, egg, wheat, or nuts. Children with this type of food allergy will react quickly — within a few minutes to a few hours*.

The parents describe having difficulties in being referred to a specialist with some of the referrals then not being completed correctly, this caused further delay to what was already a wait of many months.

There was also frustration that parents were unable to speak to a dietician earlier in the process

One parent described the additional stress of not having a repeat prescription for her baby who had been prescribed a specialist formula by her GP. This meant she had to go back to her GP each time she needed more formula. On several occasions, the chemist did not have the formula in stock which caused further anxiety.

Parents commented it was vital that healthcare professionals need to trust the parents' opinions and not to assume mums are being neurotic when raising concerns about their child’s health.

6. Case Study highlighting details of one family's journey to diagnosis.

My son was referred at 7months to a paediatrician who had originally said my son had eczema and I needed to use Aveeno cream. My son went on to have to have adrenaline administered in the back of an ambulance on the way to A&E in Manchester. The paediatrician then referred us on to Immunology and informed us this was only because he thought it was what we wanted to hear. We contacted the hospital two weeks later to chase up the referral and found no referral had been made. I then had to contact A&E and ask for the referral to be sent. The referral transpired to be a 'non-urgent referral' and we were told it would be "months" before we were seen. I then complained to PALS who suggested I contact my GP to expedite the referral.

I went back to the GP, who said, "What do you want me to do about it?" and went on to say she couldn't write a letter saying my son had an allergy because he needed a paediatrician to diagnose him with one first. I then became upset with the GP, who had a change of heart and suddenly felt able to do this. I then had to chase the practice secretary to get the request to expedite sent. It then transpired that the GP had confirmed an allergy, but not asked for the referral to be expedited as requested. This then involved another trip to the practice and seeing a different GP, more communication with the practice secretary, and finally the request to expedite was finally sent through. I then chased PALS, and chased PALS again to confirm the referral to expedite had been received.

During this emotional time, I even went to my local MP who just ignored my email.

Eventually a doctor friend suggested I write a letter to the immunologist with photos of all my son's reactions and explain what we thought had caused them. I emailed this to PALS and asked them to send it through to the immunologist's secretary. We received a phone call the following week and was told they were squeezing us in at the end of a clinic. At this appointment my child finally had the allergy tests and was diagnosed with IgE dairy, and egg allergies. The dairy and egg allergies led to my child requiring an EpiPen.

We didn't see the allergy specialists at Stepping Hill, as we live in North Reddish and therefore the MRI is closer for us. However, our GP and Health Visitor were in Stockport and I also spoke to the infant feeding team at Stepping Hill. A member of the feeding team advised us that she thought my child was just teething!

I feel lucky that I come from a background that enabled me to know how to advocate for my child, and to document everything. I have a severe allergy myself, so I knew I wasn't crazy. This was also my third child (first allergy baby) so I knew I wasn't being neurotic! A lot of people wouldn't have the same advantages, and for that reason, I really feel the system needs to change so that everyone gets a good start in life no matter their background.

7. Conclusion

Many of the families who responded to the survey were extremely dissatisfied with primary care interactions when presenting concerns about their child in relation to allergies. They felt there was a lack of understanding of food allergies in children by their GPs and associated health care professionals.

Most of the mums felt their mental health suffered considerably, many because they did not feel listened to by their GPs. Mums described being made to feel they were neurotic by health professionals they approached.

Of concern is the fact that fifteen of the mums have gone on to develop mental ill health, these include, anxiety, panic attacks, stress, and depression.

Alarmingly a total of twelve of the mums went on to be formally diagnosed with Post Natal Depression.

One mum went on to describe how her experience of her child’s allergy and poor diagnosis has gone on to affect her relationship with food and feels she still displays signs of an eating disorder. Healthcare professionals need to be aware of how a child having an allergic reaction to food can be exhausting whilst waiting for a diagnosis and this can go on to affect the whole family.

The waiting time to being referred to and seeing a specialist, including a consultant, paediatrician, dietician was highlighted by many as far too long.

Over half of the mums were offered no advice at all by their GPs around tracking their child’s symptoms and were not offered any resources.

There needs to be more information about allergies available to mums and to services to protect the mental health of parents.

We acknowledge that a group of this nature who have come together through synergies of poor experience, may or may not reflect the overall satisfaction of parents when seeking outcomes for suspected allergies in their children.

However, their experience is important and does highlight the difficulties that have been faced by this group in particular and we believe justifies the rationale to start a broader conversation around allergy diagnosis for very young children.

8. Recommendations

Recommendations and points for clarification to Stockport Clinical Commissioning Group:

a. Could we have assurance that GPs and healthcare professionals actively listen to the concerns of new parents and take them seriously, without fear of judgement of being anxious and neurotic.

b. Could any specialist formula for babies be given on a repeat prescription?

c. There appears to be long delays during the allergy referral pathway, could the CCG share the current pathway with Healthwatch Stockport, and any referral processes to a dietician?

d. The health of those children with allergies is being affected by long waiting times to see a specialist, can the CCG confirm the current waiting times for children to be seen by a specialist?

e. What support is available for families whilst they wait to see a specialist after being referred by their GP?

f. Could resources such as information leaflets or contact numbers of organisations such as Allergy UK, Stockport Allergy Mamas be available to give to new parents when an allergy is suspected?

g. What training is available, is this mandatory, and what is the uptake for GPs and health care professionals working with parents, children and babies around awareness of food allergies?

Healthwatch Stockport Recommendations to Stockport Allergy Mamas group:

- In any future studies on allergies it would help to collect details of GP practices. This will help inform whether issues with diagnosis of allergies is specific to one practice group /PCN/geographical area in Stockport.

- In any future studies details of the foods types the children are allergic too are included. This may help with the planning of any further clinical training the GPs may undertake around children with allergies.

- In any future studies include as many demographic details as possible to ensure we are reaching all sections of the community.

Comments from some participants

"It was a nightmare! I felt like I was making it all up!"

"If our journey can prevent another family waiting for 6 months or more to receive the treatment they need, then I will be grateful"

9. Next Steps

Healthwatch Stockport will send the findings of the report to the Stockport Clinical Commissioning Group.

An oversight group which will include member/s of the Stockport Allergy Mamas will be set up by Healthwatch Stockport to monitor the recommendations/points of clarification and plan an update, in a set period of time, when the recommendations can be updated, and to look if the service for these service users has improved.

Healthwatch Stockport [May 2022]

10. Dissemination

This report will be distributed to the following:

[ ] Healthwatch Stockport Board of Directors

[ ] Stockport Council Commissioning Managers

[ ] Health and Wellbeing Board

[ ] Stockport MPs

[ ] Health & Wellbeing Scrutiny Committee

[ ] Adults and Housing Scrutiny Committee

[ ] Stockport Safeguarding Adults Board

[ ] Clinical Commissioning Group commissioning Body

[ ] Viaduct Care

[ ] Council of Governors Stockport NHS Foundation Trust

[ ] Council of Governors Pennine Care

[ ] Care Quality Commission

[ ] Healthwatch England

[ ] Sector 3 and other Voluntary Organisations [state which ones]

[ ] Other [state which ones]

[ ] Healthwatch Stockport website www.healthwatchstockport.co.uk

Appendix 1.

Stockport Allergy Mumas Survey Questions

Below are the questions asked by Stockport Allergy Mumas in their survey conducted in 2021

1. How old was your child when you first had concerns about their symptoms? (If more than one child, please state all)
2. Were you advised to track symptoms or given any resources from the GP when you initially suspected something was going on/allergies?
3. Did your child attend A&E or require a hospital admission before diagnosis?
4. Did the journey to diagnosis affect your mental health? If 'Yes' please state how.
5. What do you think would have helped in the lead up to diagnosis?
6. What do you think would have helped in the lead up to diagnosis?
7. Type of allergies?
8. Were you formally diagnosed with a postnatal mental health condition?

[Ends]