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"Hope you find your 'eureka' moment soon": a qualitative study of parents/carers' online discussions around allergy, allergy tests and eczema

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Manuscripts

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1 “Hope you find your 'eureka' moment soon”: a qualitative study of parents/carers’ online discussions
2 around allergy, allergy tests and eczema

3

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1 **Objectives** To explore understandings and concerns surrounding allergy, food
2 intolerances and their potential impact on eczema amongst parents and carers of children with
3 eczema who had posted messages in online forums.

4 **Methods** We conducted a scoping review for active UK-based discussion forums that
5 did not require password/registration to view posts and identified two parenting discussion
6 forums with high activity and frequent use. We used their internal search functions to identify
7 and export discussion threads relating to allergy and allergy testing for eczema from 2011 to
8 2016. We carried out an inductive thematic analysis of the 120 exported discussion threads.

9 **Results** 246 pages of text were analysed. Analysis led to three main themes: (i)
10 confusion over the language surrounding ‘allergy’ and ‘intolerance’; (ii) diverse beliefs about
11 allergy testing in relation to eczema; and (iii) parents’ frustrations with perceptions of health
12 professionals as uninterested and unhelpful about allergy testing. Forum users were
13 concerned about immediate and delayed-type allergies but showed confusion in how terms
14 were used, as well as different approaches to testing. Parents sought experiences of others,
15 seeking social support as well as practical guidance.

16 **Conclusions** The confusion around allergy-related terminology and its possible relationship
17 with eczema means it is essential health care professionals are able to signpost parents to
18 accurate, accessible information. The lack of consistent information currently available
19 means parents may use online discussion forums as their key source of information. This
20 study suggests the confused nature of discussions on these forums are inaccurate at best, and
21 detrimental at worst.

22
23
24 Key words:
25

1 Eczema; online discussion forums; allergy; intolerance; children; qualitative

2

3 **Article Summary**

4 **Strengths and Limitations**

- 5 • Understanding the nature of online discussions could help health professionals to
6 address concerns and reach 'shared understandings' with parents/carers, as well as
7 helping parents by signposting towards accurate, reliable, and accessible information
8 online.
- 9 • As data were collected retrospectively, our analysis is limited to the data available as
10 it is impossible to ask parents to expand on posts.
- 11 • There is a possibility forum users had more difficult experiences than parents not
12 accessing forums for advice, so these results cannot be generalised outside this
13 specific environment.
- 14 • However, the consistency in concerns about allergy and intolerance in relation to
15 eczema, and the range of (often inaccurate) information shared, suggest these need
16 addressing within healthcare.

17

1 Background

2
3 Childhood eczema is very common, affecting over 20% of children aged five or under at
4 some point⁽¹⁾. Eczema can cause significant distress to the child and family due to sleep
5 disturbance and itch^(2, 3). In the majority of cases eczema starts before the age of four years
6 and clears by the teenage years, although relapses may occur⁽⁴⁾. The NICE Guideline on
7 Atopic Eczema in Children⁽⁵⁾ concludes that the main cause of treatment failure is non-
8 adherence to prescribed treatments. This may be related to a mistrust of treatments⁽⁶⁾ and the
9 mismatch of views between parents/carers and health professionals causing disillusionment
10 with treatment⁽⁷⁾. A major area where views of parents/carers and health professionals are at
11 odds is approaches to diet and allergy as a potential ‘cure’ for eczema.

12
13 Despite the popularity of dietary exclusion in eczema, there is little evidence to suggest this is
14 helpful for most people’s symptoms⁽⁸⁾. A review of dietary exclusions for the treatment of
15 eczema found little evidence that ‘few food diets’, ‘removal of milk/eggs’, and ‘elemental
16 diets’ are of benefit to individuals who have not had testing⁽⁸⁾. Furthermore, NICE guidance
17 on eczema in children states that food allergy is unlikely in eczema unless the child has
18 reacted to a food with immediate symptoms, or where moderate or severe atopic eczema has
19 not been controlled by optimum management, particularly if associated with gastrointestinal
20 symptoms⁽⁵⁾. However, people may initiate dietary exclusions for a range of perceived
21 problems, including intolerance as well as allergy⁽⁹⁾.

22
23 In 2016, 82% of adults used the internet daily or almost daily⁽¹⁰⁾: the internet is changing how
24 patients access health information and support⁽¹¹⁾. Online forums are discussion sites for
25 people to interact through asynchronous written communication⁽¹²⁾: they contain naturalistic

1 data⁽¹³⁾ and have been used widely in qualitative research⁽¹⁴⁻¹⁶⁾. Participating in online
2 forums may influence patients' experiences and has implications for our understanding of
3 patients' roles in managing their health⁽¹⁷⁾.

4
5 The permanence of written exchanges in online forums ensures future users have access to
6 both current and historical posts. Many users may turn to online forums for support^(17, 18),
7 especially if they did not understand information provided by their health care
8 professional⁽¹⁹⁾. Concerns have been raised regarding the accuracy of information found
9 online⁽²⁰⁾, but many people, particularly those with long-term health conditions, are using
10 online forums due to an unmet need for information and support⁽²¹⁾.

11
12 Qualitative research amongst parents of children with allergy has explored concerns,
13 particularly around meeting nutritional needs, development of 'picky' eating⁽²²⁾ and exploring
14 coping amongst families of children with allergy^(23, 24). Qualitative research amongst families
15 of children with eczema has explored the impact of the condition^(25, 26), information needs^{(27,}
16 ²⁸⁾, concerns about topical steroid use⁽⁶⁾ and frustrations with seeking information about
17 eczema online⁽²⁹⁾. One study explored parents' frustrations with health professionals who did
18 not appear to 'take seriously' their child's eczema; while parents saw dietary exclusions as a
19 potential cure, they perceived healthcare professionals as uninterested in this⁽⁷⁾. However, to
20 date there has been no qualitative research aimed specifically at exploring concerns around
21 diet and allergy amongst parents/carers of children with eczema.

22
23 We chose to carry out a qualitative study of discussions focused on eczema, diet and allergy
24 in online discussions as these provide a forum where users' experiences and perspectives are
25 discussed openly in a naturalistic way without researcher influence⁽³⁰⁾. This study aims to

1 explore the understandings and concerns surrounding allergy and food intolerances and their
2 potential impact on eczema among parents and carers of children with eczema who have
3 posted messages on online forums.

4 5 **Patients and methods**

6 7 *Data retrieval*

8
9 In October 2016 a scoping review was conducted (DN) to identify relevant forums. Terms
10 such as ‘eczema + elimination’ were entered into two search engines. For every search
11 conducted, 15 forums were identified or three pages of results (10 per page) were evaluated.
12 40 different forums were identified and evaluated against chosen criteria (format, registration
13 requirements, internal search functions, activity, commercial interests, site moderation, and
14 the exclusion of non-UK based forums). Two parenting websites were selected for inclusion
15 in this study as they met our selection criteria as well as showing frequent use (daily-weekly
16 posts). Registration was required to post messages, but not to view threads. Both websites
17 had site moderation (an employee who removed spam and occasionally responded to
18 comments).

19
20 DN familiarised herself with these forums, enabling a search strategy to be devised. ‘Eczema
21 exclusion’ and ‘eczema elimination’ were searched for using the internal search function.
22 The first three pages of results (10 per page) from January 2011 to October 2016 were
23 reviewed. 120 discussion threads were copied into Microsoft Word then exported into
24 qualitative data management software NVivo (version 10).

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3 1 *Ethical considerations*
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7 3 Approval was granted by the University of Southampton's Faculty of Medicine Ethics
8
9 4 Committee in July 2016 (reference 20552). This study adopted British Psychological Society
10
11 5 Guidelines⁽³¹⁾ which consider online forum messages to be within the public domain,
12
13 6 provided the researcher did not need to register in order to view them, an approach used in
14
15 7 other studies^(15, 32-34). To preserve anonymity, forums are not identified and data excerpts
16
17 8 have been paraphrased. Paraphrasing has been checked for maintaining original meaning by
18
19 9 all authors.
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22 10

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24 11 *Patient and public involvement*
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26
27 12 The following research questions arose from the James Lind Alliance Priority Setting
28
29 13 Partnership for eczema: (1) "What role might food allergy tests play in treating eczema?" (2)
30
31 14 "How much does avoidance of irritants and allergens help people with eczema?" (3) What is
32
33 15 the role of diet in treatment eczema: exclusion diets and nutritional supplements?"⁽³⁵⁾.
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39 18 This study was early scoping work, initially carried out by a medical student, in order to
40
41 19 understand public perceptions of allergy and eczema in this under-researched area. No patient
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43 20 advisers were involved in the conduct of this study. Patients and the public are involved in
44
45 21 other work on allergy and eczema being carried out by the authors.
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50 23 *Data analysis*
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1 Inductive thematic analysis⁽³⁶⁾ was conducted. One author (DN) read each discussion several
2 times and coded relevant posts line by line. Codes were derived inductively from the data
3 and grouped to produce an initial coding frame. Codes and theme/subtheme definitions were
4 iteratively developed by DN, AH, and MS through multiple team discussions. The coding
5 manual was iteratively developed and fitted and explained all of the data, having searched for
6 disconfirming cases. Data saturation was achieved. During the analysis, original posts were
7 considered within the discussion thread they were originally posted in order to retain context
8 (for example, being able to position advice to the specific question being asked).

10 **Results**

12 100,203 words were analysed, on 246 pages of text: this included 35 discussions (237 users)
13 from a general parenting forum and 50 discussions (96 users) from a baby care forum.

14 Overall, the discussions were similar in both forums: generally conversational in tone and
15 supportive in nature. Both forums are based in the United Kingdom, as were most of the
16 users (shown, for example, through references to UK hospitals). Some users explained they
17 were based abroad, especially if this provided more context to their post (for example by
18 explaining that their health care system is different from the UK).

20 Analysis of parents/carers' discussions about allergy and allergy testing highlighted three
21 main themes: (i) confusion over the language surrounding 'allergy' and 'intolerance'; (ii)
22 diverse beliefs about allergy testing in relation to eczema; and (iii) perceptions that health
23 care providers were uninterested and unhelpful about allergy testing in eczema. Selected
24 quotes are used to illustrate themes and subthemes. Paraphrased quotes are shown with
25 participant ID and forum.

Confusion surrounding ‘allergy’ and ‘intolerance’

Throughout the discussion threads there was confusion surrounding the terms ‘allergy’ and ‘intolerance’ and an apparent absence of shared understanding about their meaning. They were used interchangeably, both by individuals within posts and different users within threads.

F2-P24-1

So what are symptoms of allergy/intolerance? I'm going dairy free and my GP hasn't been helpful, saying I'm basically wasting my time.

F2-P29-1

I thought it had to be a problem with food and so while we were waiting for a dietician appointment (it took eight weeks) I eliminated the obvious allergens. You have to work out intolerances (so called slow reaction allergies) by elimination diet as allergy tests won't show them.

On occasion, allergy/intolerance would be used in a post, and someone would reply but referring to the other: in these instances, forum users appeared unaware they were referring to different conditions which could impact upon the relevance of advice. Other terms used included ‘true allergy’ and ‘major allergy’; allergies were also described as ‘bad’, and as something changeable depending on the season.

However, some users were clear in their understanding of the different terminology and how it related to the types of testing available. Terminology was often used without explanation

1 of what it meant (for example, ‘EpiPens and quick acting antihistamines’), assuming prior
2 and shared knowledge and understanding.

3 4 ***Diverse beliefs about allergy testing in relation to eczema***

5 6 *Parents feeling testing does not provide answers*

7
8 Although some users differentiated between types of testing available, often no distinction
9 was made between conventional tests in the form of skin prick tests and Specific IgE blood
10 tests, and ‘testing’ via other means such as an elimination diet or testing via ‘High Street’ or
11 internet providers using unregulated methods.

12 *F1-P6-1b*

13 *You can't really do an allergy test for it because the reactions are different – they are the type*
14 *of reactions that you need an epipen for. Maybe antihistamines. They show up straight away*
15 *so the tests just confirm the allergy really. The slow reactions are different but they won't*
16 *show up in these tests because they take a while for you to react and get things like an upset*
17 *stomach, rash and so on.*

18
19 Whilst many forum users were sharing experiences of pushing for allergy testing, several
20 users expressed concerns over this, believing that testing does not always provide answers
21 and advising caution.

22 23 *F2-P7-1*

24 *He got really bad and our doctor referred us to an allergy clinic. The only problem was that it*
25 *wasn't a paediatric clinic and they only looked for reactions linked to digestion and breathing*
26 *so they didn't spot his allergy.*

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When he was about 6 months old we managed to get in to see a consultant for blood tests. He was quite bad – one time he swelled up and came out in loads of hives from just touching wheat. They tested him for the usual stuff like dairy, nuts, wheat, soya, shellfish and they found that the poor thing was allergic to most of them. I think it's really common actually. They had loads of information about it.

F2-23-P1

I think you'll find that allergy testing is not that accurate. All the people on allergy boards will tell you this because the tests can't diagnose all allergies. It can point you in the right direction but you can't tell for sure from the tests. The only way you can really tell how your daughter's body will react is by eliminating food. My daughter's tests came back saying that she's really allergic to eggs (which she's not!) and that she's not allergic to shellfish (which she has really bad reactions to!).

*Parents feeling testing **does** provide answers*

Several parents wrote about how useful testing had been for their children, with one believing they would not have been able to ascertain their child's triggers without 'specialist testing'.

F2-P10-3

I really needed help to figure out what set his symptoms off. He is allergic to loads of stuff, with some reactions coming on straight away and others being delayed – there is just no way I could have done it without the specialists.

F2-P2-26

My little one had eczema since she was a newborn and our GP thought it would get better in time and we just had to check she didn't get an infection when it got red. I couldn't just wait

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3 1 *so I saw a nutritionist who asked us questions and then said it was milk. At first I wasn't*
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5 2 *convinced so we went for the blood test and that showed clearly she was allergic to milk as*
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7 3 *well as wheat and egg.*

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9 4 *F2-P30-2*

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12 5 *Our son's a year old and had allergies since introducing solids at 6 months. I knew he had*
13 6 *cow's milk protein allergy but it was the eczema which got us referred to the paediatrician.*
14 7 *We had allergy tests done, the usual dairy, nuts, fish etc. Best of luck, hope you find that*
15 8 *'eureka' moment soon.*

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21 10 Users who had positive experiences of allergy testing often expressed incredulity that other
22 11 families were unaware of such services, or unable to access them.

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28 13 *F2-P12-4*

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31 14 *I just can't believe how few people on here have had allergy testing! My son's skin was*
32
33 15 *horrific but when he was 12 weeks old he was diagnosed with a dairy allergy so I cut dairy*
34
35 16 *from my diet at that stage. The results were brilliant – within a week his eczema cleared up*
36
37 17 *and now he only gets the occasional patch of dry skin.*

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42 19 *F2-P29-1*

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45 20 *My son is just over a year old now. He has had allergies since we started weaning him at 6*
46
47 21 *months. The cow's milk protein allergy we knew about because he got hives from that straight*
48
49 22 *away. We ended up seeing a specialist because of his eczema and they did allergy testing, but*
50
51 23 *they could only test for the standard stuff like nuts, fish, dairy and so on. We didn't know that*
52
53 24 *we had to bring samples of the food we suspect with us to the clinic. Good luck to you, I hope*
54
55 25 *you get to the bottom of your son's symptoms.*

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3 1 *Alternatives*

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6 2 Other users talked positively about alternatives to allergy testing that lack support from
7
8 3 scientific evidence. People seemed particularly drawn to these where they were dissatisfied
9
10 4 with their clinical care.

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13 5 *F2-P17-1*

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15 6 *He is due to have allergy testing but I feel like stopping this and maybe trying Chinese*
16
17 7 *medicine.*

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22 9 *F2-P22-1*

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25 10 *We went to a naturopath who used [electrodermal non-evidence-based test] to test for*
26
27 11 *different allergies. It showed my daughter is allergic to dust mites and tomatoes. Since we*
28
29 12 *have removed these, her eczema has nearly gone in a few days. I would recommend this test,*
30
31 13 *it's non-invasive and works!*

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34 14 In a more worrying account, one user offered advice for how to test an allergen at home,
35
36 15 which would clearly be dangerous for some children and is never an appropriate action.

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41 17 *F1-P6-1a*

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44 18 *I would test the egg at home. Get [brand of liquid antihistamine] ready just in case. Find a*
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46 19 *patch of skin on his arm free from eczema, draw a small circle and dip your finger into egg*
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48 20 *white before touching the inside of the circle. Don't rub it. Wait for an itch. An anaphylactic*
49
50 21 *reaction would have happened by now and [brand of liquid antihistamine] has been effective*
51
52 22 *in the past, you can't avoid eggs and the allergist isn't concerned enough to test, so you're*
53
54 23 *not putting your son at risk. Leave for 24 hours, if there isn't a reaction then the allergy is*
55
56 24 *not there, or very mild. Give [brand of liquid antihistamine] when the itch becomes painful*

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3 1 *and red, and spreads beyond the circle or when hives appear. If his breathing becomes*
4
5 2 *difficult or if he vomits then dial 999.*
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13 5 ***Perceptions that Health Professionals are uninterested and unhelpful about allergy testing***
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17 7 Many users shared negative experiences of their GP not referring them for allergy testing,
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19 8 with some being told that allergy testing would have no benefit and to trial food elimination
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22 9 instead.
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26 11 *F1-P3-1*

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28 12 *We did a food exclusion last summer and we gave up everything for two weeks (both of us as I*
29
30 13 *was still breastfeeding) and then reintroduced each thing two weeks apart with a diary of*
31
32 14 *symptoms. Nothing appeared to make a difference. I did ask the dermatologist about allergy*
33
34 15 *testing but he seemed to think it wasn't worth it. What tests did you get?*
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39 17 *F2-P9-3*

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41
42 18 *My little boy has had eczema nearly since he was born and we had the same issues with our*
43
44 19 *GP. When he finally got referred to the allergy clinic (aged four months and we had to wait*
45
46 20 *three months for the appointment) it showed he was allergic to dairy and egg. I am still*
47
48 21 *angry about this – I sat in my doctor's office and refused to leave until I got a referral.*
49
50 22 *Doctor kept telling me the eczema would be 'non-specific' and so there was no point looking*
51
52 23 *for triggers. Well, they showed up clearly on the prick test!*
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3 1 Some parents encouraged others to ‘insist on’ a referral, even where they appeared unaware
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5 2 of the symptoms that other users’ children were experiencing, and seemed to assume they
6
7 3 were similar to their own.
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10 4

11 5 *F2-P10-1*

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14 6 *The GP’s fobbed me off by prescribing antihistamines for a while. I think if your child is that*
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16 7 *bad (and I understand as DD was the same) then you need a referral to a dermatologist/for*
17
18 8 *allergy testing and probably steroids. Allergy diagnosis and correct treatment transformed*
19
20 9 *my daughter within weeks!*
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25 11 *F2-P11-2*

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28 12 *Food triggers for us are pretty quick – if he has tomatoes, dairy or lemon he scratches almost*
29
30 13 *immediately. Same for me if I have dairy as I’m still breast feeding him, and he gets a*
31
32 14 *reaction through my milk. We’ve not been allergy tested yet – doctor said that as he seems to*
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34 15 *have a reaction then take those things out of his diet.*
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36 16

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39 17 *F2-P18-2*

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42 18 *I would insist on blood tests, DS (nearly two) was diagnosed with CMP allergy at 9 months.*
43
44 19 *I’d been completely ignored previously as I suspected it was something to do with formula. A*
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46 20 *sympathetic consultant did blood tests after taking one look at him.*
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51 22 *F2-P4-1*

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53 23 *I think my son is slightly intolerant to milk, he has many bouts of diarrhoea and can only eat*
54
55 24 *a little bit of dairy. But my GP said he’s clearly not allergic because the symptoms would be*
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3 1 worse and he does have a bottle of formula which he seems to tolerate. Can you force a GP
4 for allergy/intolerance testing? How?
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8 **Discussion**

9 *Main findings*

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13 6 Analysis of online discussions about allergy and intolerances in relation to eczema identified
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15 7
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17 8 three themes: (i) confusion over the language surrounding ‘allergy’ and ‘intolerance’; (ii)
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19 9
20 10 diverse beliefs about allergy testing in relation to eczema; and (iii) parents/carers perceiving
21
22 11 health professionals as uninterested and unhelpful around allergy testing, which many parents
23
24 12 perceive as having great potential benefit for eczema.
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30 14 The confusion surrounding terminology appeared to make it difficult for users to identify
31
32 15 whether advice was applicable to their own child. Similarly, users’ lack of distinction
33
34 16 between conventional and ‘alternative’ allergy tests makes advice difficult to interpret for
35
36 17 their own child’s circumstances. Although guidelines suggest that allergy testing is not
37
38 18 helpful for most children with eczema⁽⁵⁾, some parents perceived allergy testing to have
39
40 19 benefited their child’s eczema and were dismayed that others had not received this, while
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42 20 others advised caution, citing inconclusive or inaccurate results.
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48 *Findings in context of previous research*

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52 24 Previous qualitative research on health-focused online forums has shown them to have an
53
54 25 important role in learning from others’ experiences⁽¹⁷⁾ and gaining social support, particularly
55
56 26 for users who felt health professionals were not listening to their views. A recent meta-

1
2
3 1 synthesis highlighted how users of multiple forums sought information from ‘expert
4 patients’⁽²¹⁾. Forums provide a space in which information can be exchanged in ‘plain
5 English’⁽³⁷⁾, and often faster than through healthcare providers as users can search for
6 relevant content. Previous research examining online forums⁽¹⁷⁾ has found that conflicting
7 information from people with different experiences can cause confusion and anxiety, a
8 finding that came through strongly in our study.
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18 8 Previous research amongst parents/carers of children with eczema found frustration with
19 health professionals’ lack of interest in diet and allergy approaches as a potential ‘cure’ for
20 eczema⁽⁷⁾. Recent research showed that some parents believed eczema to have a root cause,
21 such as allergy, which needs identifying and avoiding and this is potentially a barrier to
22 treatment of the child’s eczema⁽³⁸⁾: our research echoes these findings as it shows
23 parents/carers are often confused about treatment and are interested in allergy as a possible
24 cause. We found similar frustrations in online discussion forums, possibly related to the
25 widespread belief in allergy testing for eczema conflicting with guideline advice. Numerous
26 reports have cited the need for greater education and training around allergy in both primary
27 and secondary care^(39, 40) so it is likely that parents may not receive sufficient explanation and
28 discussion when they discuss potential allergy with health professionals, leading them to seek
29 support elsewhere.
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46 21 *Strengths and limitations*

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50 23 This research reports a valuable method of exploring parents/carers’ concerns about their
51 child’s eczema. As data were collected retrospectively, our analysis is limited to the data
52 available as it is impossible to ask parents to expand on posts. It is possible that forum users
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1 had more difficult experiences than parents not accessing forums for advice, so these results
2 cannot be generalised outside this specific environment. However, the consistency in
3 concerns about allergy and intolerance in relation to eczema, and the range of (often
4 inaccurate) information shared, suggest these need addressing within healthcare.

6 *Implications for future research*

8 We found evidence of a gap in shared understanding of the role of diet and allergy, as
9 parents/carers' views in online discussion forums differ substantially from guidelines and
10 usual clinical practice. It is unsurprising that this frustrates parents and further qualitative
11 research could explore how these perceptions develop. Observation of interactions in
12 consultations, or interviews with parents about their reactions to mainstream medical
13 messages about allergy and eczema, could further elucidate how shared understandings can
14 be achieved.

16 *Implications for clinical practice*

18 Parents/carers need greater clarity and consistency in terminology surrounding 'allergy' and
19 'intolerance'. Although confusion is likely to be magnified in online discussion forums,
20 comprehensible language and clear definitions are an essential first step towards shared
21 understandings between parents and health professionals.

23 It is important that health care professionals are prepared to discuss allergy with parents and
24 signpost to accurate, reliable, and accessible information online. Without this, parents are

1 likely to turn to online discussion forums, which are confusing at best and detrimental at
2 worst.

3 4 Forum abbreviations

5
6 DC – darling child
7 DD – darling daughter
8 DS – darling son
9 OP – original post/poster
10 CMP – cow’s milk protein
11 BF – breast fed/feed/feeding
12

13 Author contribution

14
15 MS and IM designed the research study and DN collected the data. All authors were
16 involved in/commented on data analysis which was led by DN and AH and overseen by MS.
17 AH and MS developed the manuscript, to which all authors contributed and approved the
18 final version. KG and EA provided allergy-specific expertise in interpreting the data.
19

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21 There is no funding to declare.
22

23 No datasets are available for sharing.
24

25 **Competing Interests Statement**

26
27 EA has been paid personal fees to be an advisory board member on one occasion for
28 Stallergenes, Meda and Schering Plough. 1 honaria lecture Meda, 1 conference place SOSA
29 meeting ALK.
30

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COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

"Hope you find your 'eureka' moment soon": a qualitative study of parents/carers' online discussions around allergy, allergy tests and eczema

Journal:	<i>BMJ Open</i>
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Primary Subject Heading:	Dermatology
Secondary Subject Heading:	Qualitative research
Keywords:	Eczema < DERMATOLOGY, QUALITATIVE RESEARCH, PRIMARY CARE

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3 1 “Hope you find your 'eureka' moment soon”: a qualitative study of parents/carers’ online discussions
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10 4 Halls, A¹., Nunes, D²., Muller, I³., Angier, E²., Grimshaw, K^{4,5}, Santer, M³.
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1 **Objectives** To explore understandings and concerns surrounding allergy, food intolerances
2 and their potential impact on eczema amongst parents and carers of children with eczema who
3 had posted messages in online forums.

4 **Methods** We conducted a scoping review for active UK-based discussion forums that did
5 not require password/registration to view posts and identified two parenting discussion forums
6 with high activity and frequent use. We used their internal search functions to identify and export
7 discussion threads relating to allergy and allergy testing for eczema from 2011 to 2016. We
8 carried out an inductive thematic analysis of the 120 exported discussion threads.

9 **Results** 246 pages of text were analysed. Analysis led to three main themes: (i) confusion
10 over the language surrounding ‘allergy’ and ‘intolerance’; (ii) diverse beliefs about allergy
11 testing in relation to eczema; and (iii) parents’ frustrations with perceptions of health
12 professionals as uninterested and unhelpful about allergy testing. Forum users were concerned
13 about immediate and delayed-type allergies but showed confusion in how terms were used, as
14 well as different approaches to testing. Parents sought experiences of others, seeking social
15 support as well as practical guidance.

16 **Conclusions** The confusion around allergy-related terminology and its possible relationship
17 with eczema means it is essential health care professionals are able to signpost parents to
18 accurate, accessible information. The lack of consistent information currently available means
19 parents may use online discussion forums as an important source of information. This study
20 suggests the confused nature of discussions on these forums are inaccurate at best, and
21 detrimental at worst.

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3 1 Key words:
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8 3 Eczema; online discussion forums; allergy; intolerance; children; qualitative
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12 5 **Article Summary**

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15 6 Strengths and limitations of this study

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17 7 • The use of forum posts covering a five-year span means that current and historical posts
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19 8 were included in the analysis, allowing for a range, and potential change, in views to be
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21 9 explored. As data were collected retrospectively, our analysis is limited to the data
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23 10 available as it is impossible to ask parents to expand on posts.
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26 11 • There is a possibility forum users had more difficult experiences than parents not
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28 12 accessing forums for advice, so these results cannot be generalised outside this specific
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31 13 environment.
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1 Background

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3 Childhood eczema is very common, affecting over 20% of children aged five or under at some
4 point⁽¹⁾. Eczema can cause significant distress to the child and family due to sleep disturbance
5 and itch^(2, 3). In the majority of cases eczema starts before the age of four years and clears by the
6 teenage years, although relapses may occur⁽⁴⁾. The NICE Guideline on Atopic Eczema in
7 Children⁽⁵⁾ concludes that the main cause of treatment failure is non-adherence to prescribed
8 treatments. This may be related to a mistrust of treatments⁽⁶⁾ and the mismatch of views between
9 parents/carers and health professionals causing disillusionment with treatment⁽⁷⁾. A major area
10 where views of parents/carers and health professionals are at odds is approaches to diet and
11 allergy as a potential ‘cure’ for eczema.

12
13 Despite the popularity of dietary exclusion in eczema, there is little evidence to suggest this is
14 helpful for most people’s symptoms⁽⁸⁾. A review of dietary exclusions for the treatment of
15 eczema found little evidence that ‘few food diets’, ‘removal of milk/eggs’, and ‘elemental diets’
16 are of benefit to individuals who have not had testing⁽⁸⁾. Furthermore, NICE guidance on eczema
17 in children states that food allergy is unlikely in eczema unless the child has reacted to a food
18 with immediate symptoms, or where moderate or severe atopic eczema has not been controlled
19 by optimum management, particularly if associated with gastrointestinal symptoms⁽⁵⁾. However,
20 people may initiate dietary exclusions for a range of perceived problems, including intolerance as
21 well as allergy⁽⁹⁾.

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3 1 In 2017, 80% of adults used the internet daily or almost daily⁽¹⁰⁾: the internet is changing how
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5 2 patients access health information and support⁽¹¹⁾. Online forums are discussion sites for people
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7 3 to interact through asynchronous written communication⁽¹²⁾: they contain naturalistic data⁽¹³⁾ and
8
9 4 have been used widely in qualitative research⁽¹⁴⁻¹⁶⁾. Participating in online forums may
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11 5 influence patients' experiences and has implications for our understanding of patients' roles in
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13 6 managing their health⁽¹⁷⁾.

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19 8 The permanence of written exchanges in online forums ensures future users have access to both
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21 9 current and historical posts. Many users may turn to online forums for support^(17, 18), especially
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23 10 if they did not understand information provided by their health care professional⁽¹⁹⁾. Concerns
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25 11 have been raised regarding the accuracy of information found online⁽²⁰⁾, but many people,
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27 12 particularly those with long-term health conditions, are using online forums due to an unmet
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29 13 need for information and support⁽²¹⁾.

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35 15 Qualitative research amongst parents of children with allergy has explored concerns, particularly
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37 16 around meeting nutritional needs, development of 'picky' eating⁽²²⁾ and exploring coping
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39 17 amongst families of children with allergy^(23, 24). Qualitative research amongst families of children
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41 18 with eczema has explored the impact of the condition^(25, 26), information needs^(27, 28), concerns
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43 19 about topical steroid use⁽⁶⁾ and frustrations with seeking information about eczema online⁽²⁹⁾.
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45 20 One study explored parents' frustrations with health professionals who did not appear to 'take
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47 21 seriously' their child's eczema; while parents saw dietary exclusions as a potential cure, they
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49 22 perceived healthcare professionals as uninterested in this⁽⁷⁾. However, to date there has been no
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1 qualitative research aimed specifically at exploring concerns around diet and allergy amongst
2 parents/carers of children with eczema.

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4 We chose to carry out a qualitative study of discussions focused on eczema, diet and allergy in
5 online discussions as these provide a forum where users' experiences and perspectives are
6 discussed openly in a naturalistic way without researcher influence⁽³⁰⁾. This study aims to
7 explore the understandings and concerns surrounding allergy and food intolerances and their
8 potential impact on eczema among parents and carers of children with eczema who have posted
9 messages on online forums.

11 Patients and methods

13 *Data retrieval*

14
15 In October 2016 a scoping review was conducted (by DN, a medical student, supervised by MS,
16 an academic GP, and AH, a research fellow, both with qualitative expertise) to identify relevant
17 forums. The terms 'eczema + exclusion' and 'eczema + elimination' were entered into two search
18 engines (Google and Bing). For every search conducted, 15 forums were identified or three
19 pages of results (10 per page) were evaluated. This process identified 40 different forums, which
20 were evaluated against chosen criteria (format, registration requirements, internal search
21 functions, activity (how frequent posts were, such as daily, weekly, monthly), commercial
22 interests, site moderation, and the exclusion of non-UK based forums). Two parenting websites
23 were selected for inclusion in this study as they met our selection criteria as well as showing

1 frequent use (daily-weekly posts). Registration was required to post messages, but not to view
2 threads. Both websites had site moderation (an employee who removed spam and occasionally
3 responded to comments).

4
5 DN familiarised herself with these forums, enabling a search strategy to be devised. 'Eczema
6 exclusion' and 'eczema elimination' were searched for using the internal search function. The
7 first three pages of results (10 per page) from January 2011 to October 2016 were reviewed. 120
8 discussion threads were copied into Microsoft Word then exported into qualitative data
9 management software NVivo (version 10).

11 *Ethical considerations*

12
13 Approval was granted by the University of Southampton's Faculty of Medicine Ethics
14 Committee in July 2016 (reference 20552). This study adopted British Psychological Society
15 Guidelines⁽³¹⁾ which consider online forum messages to be within the public domain, provided
16 the researcher did not need to register in order to view them, an approach used in other studies<sup>(15,
17 32-34)</sup>. To preserve anonymity, forums are not identified and data excerpts have been
18 paraphrased. Paraphrasing has been checked for maintaining original meaning by all authors.

20 *Patient and public involvement*

21 The following research questions arose from the James Lind Alliance Priority Setting Partnership
22 for eczema: (1) "What role might food allergy tests play in treating eczema?" (2) "How much

1 does avoidance of irritants and allergens help people with eczema?" (3) What is the role of diet
2 in treatment eczema: exclusion diets and nutritional supplements?"⁽³⁵⁾.

3
4 This study was early scoping work, initially carried out by a medical student, in order to
5 understand public perceptions of allergy and eczema in this under-researched area. No patient
6 advisers were involved in the conduct of this study. Patients and the public are involved in other
7 work on allergy and eczema being carried out by the authors.

8 9 10 *Data analysis*

11
12 Inductive thematic analysis⁽³⁶⁾ was conducted. One author (DN) read each discussion several
13 times and coded relevant posts line by line. Codes were derived inductively from the data and
14 grouped to produce an initial coding frame. Codes and theme/subtheme definitions were
15 iteratively developed by DN, AH, and MS through multiple team discussions. The coding
16 manual was iteratively developed and fitted and explained all of the data, having searched for
17 disconfirming cases. Data saturation was achieved. During the analysis, original posts were
18 considered within the discussion thread they were originally posted in order to retain context (for
19 example, being able to position advice to the specific question being asked).

20 21 **Results**

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1 100,203 words were analysed, on 239 pages of text: this included 31 discussions (159 users)
 2 from a general parenting forum and 51 discussions (96 users) from a baby care forum. This is
 3 shown in Table 1. Overall, the discussions were similar in both forums: generally conversational
 4 in tone and supportive in nature. Both forums are based in the United Kingdom, as were most of
 5 the users (shown, for example, through references to UK hospitals). Some users explained they
 6 were based abroad, especially if this provided more context to their post (for example by
 7 explaining that their health care system is different from the UK).

8
 9 Table 1

Forum	F1 (general parenting)	F2 (baby care)
Total users	159	96
Number of pages of text	113	126
Total included threads	31	51
Median posts per thread (range)	12 (2 to 31)	4 (1 to 26)
Median users per thread (range)	7 (1 to 15)	3 (1 to 9)
Medianposts per user over all threads (range)	16	1 to 40

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1 Analysis of parents/carers' discussions about allergy and allergy testing highlighted three main
2 themes: (i) confusion over the language surrounding 'allergy' and 'intolerance'; (ii) diverse
3 beliefs about allergy testing in relation to eczema; and (iii) perceptions that health care providers
4 were uninterested and unhelpful about allergy testing in eczema. Selected quotes are used to
5 illustrate themes and subthemes. Paraphrased quotes are shown with participant ID and forum.

6 ***Confusion surrounding 'allergy' and 'intolerance'***

7
8
9 Throughout the discussion threads there was confusion surrounding the terms 'allergy' and
10 'intolerance' and an apparent absence of shared understanding about their meaning. They were
11 used interchangeably, both by individuals within posts and different users within threads.

12 *F2-P24-1*

13 *So what are symptoms of allergy/intolerance? I'm going dairy free and my GP hasn't been*
14 *helpful, saying I'm basically wasting my time.*

15
16 *F2-P29-1*

17 *I thought it had to be a problem with food and so while we were waiting for a dietician*
18 *appointment (it took eight weeks) I eliminated the obvious allergens. You have to work*
19 *out intolerances (so called slow reaction allergies) by elimination diet as allergy tests*
20 *won't show them.*

21
22 On occasion, allergy/intolerance would be used in a post, and someone would reply but referring
23 to the other: in these instances, forum users appeared unaware they were referring to different
24 conditions which could impact upon the relevance of advice. Other terms used included 'true

1 allergy' and 'major allergy'; allergies were also described as 'bad', and as something changeable
2 depending on the season.

3
4 However, some users were clear in their understanding of the different terminology and how it
5 related to the types of testing available. Terminology was often used without explanation of
6 what it meant (for example, 'EpiPens and quick acting antihistamines'), assuming prior and
7 shared knowledge and understanding.

8 9 ***Diverse beliefs about allergy testing in relation to eczema***

10 11 *Parents feeling testing does not provide answers*

12
13 Although some users differentiated between types of testing available, often no distinction was
14 made between conventional tests in the form of skin prick tests and Specific IgE blood tests, and
15 'testing' via other means such as an elimination diet or testing via 'High Street' or internet
16 providers using unregulated methods.

17 *F1-P6-1b*

18 *You can't really do an allergy test for it because the reactions are different – they are the type of*
19 *reactions that you need an epipen for. Maybe antihistamines. They show up straight away so the*
20 *tests just confirm the allergy really. The slow reactions are different but they won't show up in*
21 *these tests because they take a while for you to react and get things like an upset stomach, rash*
22 *and so on.*

1
2
3 1 Whilst many forum users were sharing experiences of pushing for allergy testing, several users
4
5 2 expressed concerns over this, believing that testing does not always provide answers and
6
7
8 3 advising caution.
9
10 4

11
12 5 *F2-23-P1*

13
14 6 *I think you'll find that allergy testing is not that accurate. All the people on allergy boards will*
15
16 7 *tell you this because the tests can't diagnose all allergies. It can point you in the right direction*
17
18 8 *but you can't tell for sure from the tests. The only way you can really tell how your daughter's*
19
20 9 *body will react is by eliminating food. My daughter's tests came back saying that she's really*
21
22 10 *allergic to eggs (which she's not!) and that she's not allergic to shellfish (which she has really*
23
24 11 *bad reactions to!).*
25
26 12

27
28 13 *Parents feeling testing **does** provide answers*

29
30
31 14 Several parents wrote about how useful testing had been for their children, with one believing
32
33 15 they would not have been able to ascertain their child's triggers without 'specialist testing'.
34
35

36
37 16 *F2-P10-3*

38
39 17 *I really needed help to figure out what set his symptoms off. He is allergic to loads of stuff, with*
40
41 18 *some reactions coming on straight away and others being delayed – there is just no way I could*
42
43 19 *have done it without the specialists.*
44
45

46
47 20 *F2-P2-26*

48
49 21 *My little one had eczema since she was a newborn and our GP thought it would get better in time*
50
51 22 *and we just had to check she didn't get an infection when it got red. I couldn't just wait so I saw a*
52
53 23 *nutritionist who asked us questions and then said it was milk. At first I wasn't convinced so we*
54
55 24 *went for the blood test and that showed clearly she was allergic to milk as well as wheat and egg.*
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3 1 *F2-P30-2*

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5
6 2 *Our son's a year old and had allergies since introducing solids at 6 months. I knew he had cow's*
7 *milk protein allergy but it was the eczema which got us referred to the paediatrician. We had*
8 *allergy tests done, the usual dairy, nuts, fish etc. Best of luck, hope you find that 'eureka' moment*
9 *soon.*
10
11
12
13 6

14
15 7 Users who had positive experiences of allergy testing often expressed incredulity that other
16
17 8 families were unaware of such services, or unable to access them.
18
19
20
21 9

22
23
24 10 *F2-P12-4*

25
26 11 *I just can't believe how few people on here have had allergy testing! My son's skin was horrific*
27 *but when he was 12 weeks old he was diagnosed with a dairy allergy so I cut dairy from my diet*
28 *at that stage. The results were brilliant – within a week his eczema cleared up and now he only*
29 *gets the occasional patch of dry skin.*
30
31
32
33 14

34
35 15 *Alternatives*

36
37
38 16 Other users talked positively about alternatives to allergy testing that lack support from scientific
39
40 17 evidence. People seemed particularly drawn to these where they were dissatisfied with their
41
42 18 clinical care.
43
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46 19 *F2-P17-1*

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49 20 *He is due to have allergy testing but I feel like stopping this and maybe trying Chinese medicine.*
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53 21

54 22 *F2-P22-1*
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3 1 *We went to a naturopath who used [electrodermal non-evidence-based test] to test for different*
4
5 2 *allergies. It showed my daughter is allergic to dust mites and tomatoes. Since we have removed*
6
7 3 *these, her eczema has nearly gone in a few days. I would recommend this test, it's non-invasive*
8
9 4 *and works!*

11
12 5 In a more worrying account, one user offered advice for how to test an allergen at home, which
13
14 6 would clearly be dangerous for some children and is never an appropriate action.
15
16
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18
19

20 8 *F1-P6-1a*

21
22
23 9 *I would test the egg at home. Get [brand of liquid antihistamine] ready just in case. Find a*
24
25 10 *patch of skin on his arm free from eczema, draw a small circle and dip your finger into egg white*
26
27 11 *before touching the inside of the circle. Don't rub it. Wait for an itch. An anaphylactic reaction*
28
29 12 *would have happened by now and [brand of liquid antihistamine] has been effective in the past,*
30
31 13 *you can't avoid eggs and the allergist isn't concerned enough to test, so you're not putting your*
32
33 14 *son at risk. Leave for 24 hours, if there isn't a reaction then the allergy is not there, or very mild.*
34
35 15 *Give [brand of liquid antihistamine] when the itch becomes painful and red, and spreads beyond*
36
37 16 *the circle or when hives appear. If his breathing becomes difficult or if he vomits then dial 999.*
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47 19 ***Perceptions that Health Professionals are uninterested and unhelpful about allergy testing***

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49 20
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51 21 Many users shared negative experiences of their GP not referring them for allergy testing, with
52
53 22 some being told that allergy testing would have no benefit and to trial food elimination instead.
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3 1 *F1-P3-1*

4
5 2 *We did a food exclusion last summer and we gave up everything for two weeks (both of us as I*
6
7 3 *was still breastfeeding) and then reintroduced each thing two weeks apart with a diary of*
8
9 4 *symptoms. Nothing appeared to make a difference. I did ask the dermatologist about allergy*
10
11 5 *testing but he seemed to think it wasn't worth it. What tests did you get?*
12
13

14 6
15
16
17 7 *F2-P9-3*

18
19
20 8 *My little boy has had eczema nearly since he was born and we had the same issues with our GP.*
21
22 9 *When he finally got referred to the allergy clinic (aged four months and we had to wait three*
23
24 10 *months for the appointment) it showed he was allergic to dairy and egg. I am still angry about*
25
26 11 *this – I sat in my doctor's office and refused to leave until I got a referral. Doctor kept telling me*
27
28 12 *the eczema would be 'non-specific' and so there was no point looking for triggers. Well, they*
29
30 13 *showed up clearly on the prick test!*
31
32

33 14
34
35 15
36
37 16 Some parents encouraged others to 'insist on' a referral, even where they appeared unaware of
38
39 17 the symptoms that other users' children were experiencing, and seemed to assume they were
40
41
42 18 similar to their own.
43

44 19
45
46 20 *F2-P10-1*

47
48
49 21 *The GP's fobbed me off by prescribing antihistamines for a while. I think if your child is that bad*
50
51 22 *(and I understand as DD was the same) then you need a referral to a dermatologist/for allergy*
52
53 23 *testing and probably steroids. Allergy diagnosis and correct treatment transformed my daughter*
54
55 24 *within weeks!*
56
57
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1

2

F2-P18-2

3

I would insist on blood tests, DS (nearly two) was diagnosed with CMP allergy at 9 months. I'd been completely ignored previously as I suspected it was something to do with formula. A sympathetic consultant did blood tests after taking one look at him.

4

5

F2-P4-1

6

I think my son is slightly intolerant to milk, he has many bouts of diarrhoea and can only eat a little bit of dairy. But my GP said he's clearly not allergic because the symptoms would be worse and he does have a bottle of formula which he seems to tolerate. Can you force a GP for allergy/intolerance testing? How?

7

Discussion

8

Main findings

9

Analysis of online discussions about allergy and intolerances in relation to eczema identified three themes: (i) confusion over the language surrounding 'allergy' and 'intolerance'; (ii) diverse beliefs about allergy testing in relation to eczema; and (iii) parents/carers perceiving health professionals as uninterested and unhelpful around allergy testing, which many parents perceive as having great potential benefit for eczema.

10

1 The confusion surrounding terminology appeared to make it difficult for users to identify
2 whether advice was applicable to their own child. Similarly, users' lack of distinction between
3 conventional and 'alternative' allergy tests makes advice difficult to interpret for their own
4 child's circumstances. Although guidelines suggest that allergy testing is not helpful for most
5 children with eczema⁽⁵⁾, some parents perceived allergy testing to have benefited their child's
6 eczema and were dismayed that others had not received this, while others advised caution, citing
7 inconclusive or inaccurate results.

8

9 *Findings in context of previous research*

10

11 Previous qualitative research on health-focused online forums has shown them to have an
12 important role in learning from others' experiences⁽¹⁷⁾ and gaining social support, particularly for
13 users who felt health professionals were not listening to their views. A recent meta-synthesis
14 highlighted how users of multiple forums sought information from 'expert patients'⁽²¹⁾. Forums
15 provide a space in which information can be exchanged in 'plain English'⁽³⁷⁾, and often faster
16 than through healthcare providers as users can search for relevant content. Previous research
17 examining online forums⁽¹⁷⁾ has found that conflicting information from people with different
18 experiences can cause confusion and anxiety, a finding that came through strongly in our study.

19

20 Previous research amongst parents/carers of children with eczema found frustration with health
21 professionals' lack of interest in diet and allergy approaches as a potential 'cure' for eczema, as
22 well as frustration relating to conflicting advice offered by different health professionals⁽⁷⁾.

23 Recent research showed that some parents believed eczema to have a root cause, such as allergy,

1 which needs identifying and avoiding and this is potentially a barrier to treatment of the child's
2 eczema⁽³⁸⁾: our research echoes these findings as it shows parents/carers are often confused about
3 treatment and are interested in allergy as a possible cause. We found similar frustrations in
4 online discussion forums, possibly related to the widespread belief in allergy testing for eczema
5 conflicting with guideline advice. Numerous reports have cited the need for greater education
6 and training around allergy in both primary and secondary care^(39, 40) so it is likely that parents
7 may not receive sufficient explanation and discussion when they discuss potential allergy with
8 health professionals, leading them to seek support elsewhere.

9 10 *Strengths and limitations*

11
12 This research reports a valuable method of exploring parents/carers' concerns about their child's
13 eczema. As data were collected retrospectively, our analysis is limited to the data available as it
14 is impossible to ask parents to expand on posts. The searches identified a large quantity of
15 relevant information, although it is possible that using different search terms may have yielded
16 different findings. Forum users may have had more difficult experiences than parents not
17 accessing forums for advice, so these results cannot be generalised outside this specific
18 environment. However, the consistency in concerns about allergy and intolerance in relation to
19 eczema, and the range of (often inaccurate) information shared, suggest these need addressing
20 within healthcare.

21 22 *Implications for future research*

23

1 We found evidence of a gap in shared understanding of the role of diet and allergy, as
2 parents/carers' views in online discussion forums differ substantially from guidelines and usual
3 clinical practice. It is unsurprising that this frustrates parents and further qualitative research
4 could explore how these perceptions develop. Observation of interactions in consultations, or
5 interviews with parents about their reactions to mainstream medical messages about allergy and
6 eczema, could further elucidate how shared understandings can be achieved.

8 *Implications for clinical practice*

9
10 Parents/carers need greater clarity and consistency in terminology surrounding 'allergy' and
11 'intolerance'. Although confusion is likely to be magnified in online discussion forums,
12 comprehensible language and clear definitions are an essential first step towards shared
13 understandings between parents and health professionals.

14
15 It is important that health care professionals are prepared to discuss allergy with parents and
16 signpost to accurate, reliable, and accessible information online. Without this, parents are likely
17 to turn to online discussion forums, which are confusing at best and detrimental at worst.

18 19 Forum abbreviations

20
21 DC – darling child
22 DD – darling daughter
23 DS – darling son
24 OP – original post/poster
25 CMP – cow's milk protein
26 BF – breast fed/feed/feeding

27 28 Author contribution

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2
3 1
4
5 2 MS and IM designed the research study and DN collected the data. All authors were involved
6
7 3 in/commented on data analysis which was led by DN and AH and overseen by MS. AH and MS
8
9 4 developed the manuscript, to which all authors contributed and approved the final version. KG
10
11 5 and EA provided allergy-specific expertise in interpreting the data.
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18
19 8
20
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22
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24
25 11 Health Research School for Primary Care Research (NIHR SPCR). The views expressed are
26
27 12 those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health
28
29 13 and Social Care.
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33 14
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35 15 No datasets are available for sharing.
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40 **Competing Interests Statement**

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42 18
43
44 19 EA has been paid personal fees to be an advisory board member on one occasion for
45
46 20 Stallergenes, Meda and Schering Plough. 1 honaria lecture Meda, 1 conference place SOSA
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48 21 meeting ALK. KG reports personal fees from Nutricia, personal fees from Abbott, personal fees
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50 22 from Mead Johnson, personal fees from Nestle, personal fees from Reacta Biotech, outside the
51
52 23 submitted work.
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2 Data Sharing Statement

3

4 Requests for data will be considered by the authors.

5

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COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.