

# **Section 3 Symptoms and diagnosis**

### Section 3: Experience of symptoms and diagnosis

#### Symptoms at diagnosis

- The most common symptoms leading to diagnosis were rash-like symptoms (n=38, 38.00%) followed by thickened, cracked, dry, scaly skin (n=23, 23.00%) and allergies that led to the diagnosis of AD (n=17, 17.00%). There were also 25 participants (25.00%) that were unable to describe specifically what led to their diagnosis as they were a child or infant at the time.
- There were a number of sub-group variations. Participants that were high school or trade education reported having allergies that led to diagnosis more frequently than the general cohort (28.57% compared to 17.00% in the general cohort). Participants with mild AD reported having red to brownish-grey patches that led to diagnosis more frequently than the general cohort (54.55% compared to 15.00% in the general cohort) while participants with moderate AD reported this symptom less frequently (3.85% compared with 15.00% in the general cohort).
- There were various combinations of diagnostic tests conducted with the most common tests recalled being skin examination only (n=41, 41.00%) followed by skin examination, blood test, patch test and review of medical history (n=24, 24.00%).
- There was one sub-group variation. Participants with mild AD reported having a skin examination only, more frequently than the general cohort (90.91% compared to 41.00% in the general cohort) and they did not report having other tests such as blood tests, patch tests or review of medical history.
- 64 participants (64.00%) noted that they had no support at diagnosis, (n=21; 21.00%) reported having some support, but not enough and (n=15, 15.00) reported having enough support.
- There were a number of sub-group variations. Participants with mild AD reported having no support more frequently than the general cohort (81.82% compared to 64.00% in the general cohort). Participants with moderate AD reported having enough support less frequently than the general cohort (3.85% compared to 15.00% in the general cohort).

#### Genetic/biomarker tests

- Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. The majority of participants (n=96; 96.00%) had not had a discussion while four participants (4.00%) stated they had had a discussion about this kind of test of which, two brought the topic up with their doctor.
- Participants were also asked about their interest in this type of test if it was available. The majority of participants (n=89, 89.00%) were interested in having it if it were available, three participants (3.00%) indicated that they paid for this test themselves while eight participants (8.00%) indicated that they were not interested in this type of test.

#### Knowledge of condition and prognosis

- In relation to how much participants knew about their condition at diagnosis, the main theme was that participants, or their parents, knew nothing or very little about their condition (n=45, 45.00%). 18 participants (18.00%) described having some knowledge about AD and this was primarily due to having another family member who also had the condition. There were also 19 participants (19.00%) that commented that they have lived their whole life with AD and it is therefore the only way of life that they knew.
- There was one sub-group variation in relation to participants that have very severe AD who reported knowing about AD through other family members, more frequently than the general cohort (31.82% compared to 18.00% in the general cohort).
- Participants were asked whether anyone talked to them about prognosis. Over half of the participants (n=54, 54.00%) described that they understood that AD was a lifelong condition and did not expect it to get better. 22 participants (22.00%) that noted that they did not have a clear prognosis and these participants also spoke about the uncertainty of their situation.
- There were two sub-group variations. Participants with mild AD reported their prognosis as being something they will have for their lifetime less frequently than the general cohort (27.27% compared to 54.00% in the general cohort). Participants with very severe AD reported having their AD under control less frequently than the general cohort (4.55% compared to 18.00% in the general cohort).

### Experience of symptoms before diagnosis

Participants were asked to recall the symptoms that they noticed in themselves that led them to pursue further investigation with a clinician. This question was asked both in an online questionnaire and as part of the structured interview. Responses from both sources of information were cross-validated to compile these results. Participants were asked which symptoms led them to being diagnosed with AD. The most common symptoms described by all participants were rash-like symptoms (n=38, 38.00%) followed by thickened, cracked, dry, scaly skin (n=23, 23.00%) and allergies that led to the diagnosis of AD (n=17, 17.00%). There were also 25 participants (25.00%)

that were unable to describe specifically what led to their diagnosis as they were a child or infant at the time.

There were a number of sub-group variations. Participants that were high school or trade education reported having allergies that led to diagnosis more frequently than the general cohort (28.57% compared to 17.00% in the general cohort). Participants with mild AD reported having red to brownish-grey patches that led to diagnosis more frequently than the general cohort (54.55% compared to 15.00% in the general cohort) while participants with moderate AD reported this symptom less frequently (3.85% compared with 15.00% in the general cohort).

Table 3.1: Symptoms leading to diagnosis

Symptoms leading to diagnosis	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Rash-like symptoms (generally blotchy described as AD)	38	38.00	3	27.27	9	34.62	17	41.46	9	40.91
Unable to recall as they were a child	25	25.00	2	18.18	9	34.62	8	19.51	6	27.27
Thickened, cracked, dry, scaly skin	23	23.00	1	9.09	4	15.38	11	26.83	7	31.82
Allergies leading to diagnosis	17	17.00	1	9.09	4	15.38	8	19.51	4	18.18
Red to brownish-grey patches, especially on the hands, feet, ankles, wrists, neck, upper chest, eyelids, inside the bend of the elbows and knees	15	15.00	6	54.55	1	3.85	5	12.20	3	13.64
Itching, which is severe and not controlled	13	13.00	1	9.09	5	19.23	4	9.76	3	13.64
Itching, which is uncomfortable but reasonably controlled	10	10.00	1	9.09	1	3.85	6	14.63	2	9.09
Small, raised bumps, which may leak fluid and crust over when scratched	3	3.00	0	0.00	1	3.85	1	2.44	1	4.55
Sores (lesions) that may become infected by bacteria or viruses	2	2.00	0	0.00	0	0.00	2	4.88	0	0.00

Symptoms leading to diagnosis	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Rash-like symptoms (generally blotchy described as AD)	14	35.90	17	41.46	21	35.59	21	36.21	17	40.48
Unable to recall as they were a child	13	33.33	12	29.27	13	22.03	16	27.59	9	21.43
Thickened, cracked, dry, scaly skin	13	33.33	10	24.39	13	22.03	13	22.41	10	23.81
Allergies leading to diagnosis	6	15.38	6	14.63	11	18.64	5	8.62	12	28.57
Red to brownish-grey patches, especially on the hands, feet, ankles, wrists, neck, upper chest, eyelids, inside the bend of the elbows and knees	5	12.82	3	7.32	12	20.34	8	13.79	7	16.67
Itching, which is severe and not controlled	7	17.95	3	7.32	10	16.95	5	8.62	8	19.05
Itching, which is uncomfortable but reasonably controlled	2	5.13	3	7.32	7	11.86	4	6.90	6	14.29
Small, raised bumps, which may leak fluid and crust over when scratched	1	2.56	1	2.44	2	3.39	3	5.17	0	0.00
Sores (lesions) that may become infected by bacteria or viruses	1	2.56	1	2.44	1	1.69	2	3.45	0	0.00

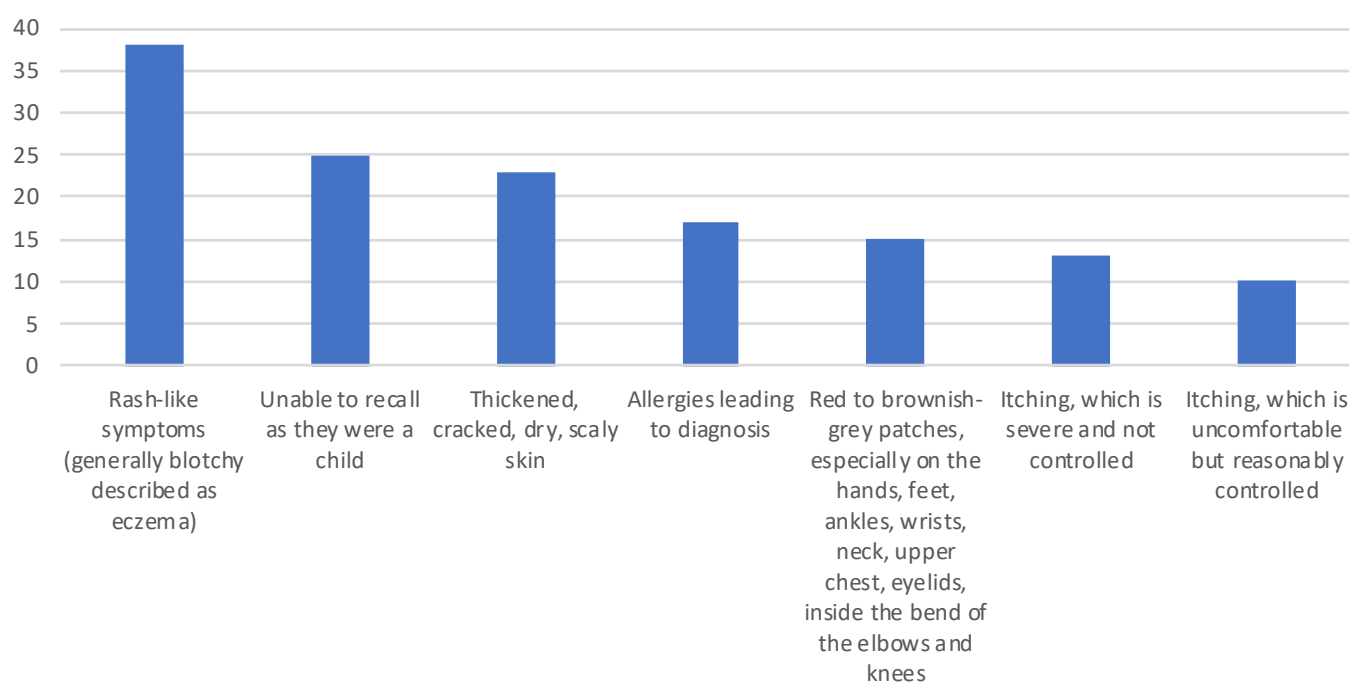


Figure 3.1: Symptoms experienced at diagnosis

As noted, participants were asked to describe the symptoms that led to their diagnosis. Exemplars of these descriptions are provided below:

#### Rash-like symptoms

*There were these rashes in parts of my body and after seeing the doctor with my parents, that was what I was diagnosed with. That's how I knew I had it.* **Participant 15**

*I was just covered in rashes and so on. I think it was a no brainer for the doctors even in those days...so it was blatantly obvious that I had eczema.* **Participant 30**

*Yeah of course, so I was seven years old, we'd recently moved to a new house in LOCATION and it was something that we ... Well I personally at that point, looking back on it now, I was seven so I didn't really fathom what it meant, but it was sort of deemed to be insignificant. What happened was I got a little bit of a rash on my foot, and we thought maybe I had an allergic reaction to a tree that we had in our new house, something like that. There were so many things it could have been ... that could have dictated what that was, so my first experience with eczema was quite literally a little tiny rash on my left foot, and I had no idea that it would end up dictating a bit part of my life.* **Participant 54**

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#### Thickened, cracked, dry, scaly skin

*And then it got worse when I started working in care, which I'm currently working in, in healthcare. So that means I get frequent hand washing, and it was all flaky and scaly and really irritated, so like with moisture gone. I think I went to the doctor's, like ... I'm not sure actually, a while ago actually, because it started to flare up and get really red and raised, so they told me, "Okay, you've got atopic dermatitis"* **Participant 21**

*Yeah, sure. So, I was apparently born with really dry, strange skin. And by about two years old, I was diagnosed with eczema, so I've always experienced the symptoms of it. So, I can't really reflect on when it first started, because it's always been what I've known.* **Participant 34**

*Well, it wasn't me who noticed, it was mum. I was a baby still. She... dry skin, scaly. I was always irritated and trying to scratch myself. My skin was red. As I grew older, it was more kind of the white patches because I have dark skin. It was white patches, dry, and scales. Mainly scratching, especially around my eyes and stuff. Yeah, messing and what not. Yeah, that's what she noticed.* **Participant 61**

**Allergies leading to diagnosis**

*I think it chained through because I also have food allergy. It went hand-in-hand with that. It was like when one was diagnosed, the other was picked up as well. **Participant 26***

*When I was 18, I just moved to start Uni. I used to get - because I have a lot of allergies as well, so I would occasionally have reactions from allergies when I've eaten something and I realized that my lips and mouth was very itchy. That was the first time that I realized that something wasn't right and I ended up with eczema all over my face from just starting then. That was probably a month or something until I went for a doctor and then the GP said it was eczema and gave me a prescription for steroid cream and booked me into a dermatologist. I'm not sure, I think by the time that I went to the dermatologist it had gone down from using the creams, but she said it was eczema. **Participant 45***

*We went to a specialist, we were referred to a specialist, he has given us some advice on how to treat Eczema. We went to have his pretest to see whether he has, what allergies he is reacting to, or food allergies. All those things, in other words, have been established as he has got Eczema. **Participant 81***

**Itching, which is severe and not controlled**

*I was only a few months old. It was so severe that I developed the ability to scratch before a baby should. **Participant 26***

*I was always irritated and trying to scratch myself. My skin was red. As I grew older, it was more kind of the white patches because I have dark skin. It was white patches, dry, and scales. Mainly scratching, especially around my eyes and stuff. Yeah, messing and what not. Yeah, that's what she noticed. **Participant 61***

*My skin just went crazy. It was just flaring up all the time. I couldn't handle it, couldn't maintain it. What doctors said when I was about 15, I think? 15 to 17 and it was just, it wouldn't calm down. Yeah, it was pretty unbearable. **Participant 79***

### Diagnostic tests

Participants were asked to recall the types of tests they had to diagnose their AD. There were various combinations of diagnostic tests conducted with the most common tests recalled being skin examination only (n=41, 41.00%) followed by skin examination, blood test, patch test and review of medical history

(n=24, 24/00%). There was one sub-group variation. Participants with mild AD reported having a skin examination only, more frequently than the general cohort (90.91% compared to 41.00% in the general cohort) and they did not report having other tests such as blood tests, patch tests or review of medical history.

Table 3.2: Diagnostic tests

Diagnostic tests	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Skin examination only	41	41.00	10	90.91	12	46.15	12	29.27	7	31.82
Skin examination, blood test, patch test and review of medical history	24	24.00	0	0.00	4	15.38	15	36.59	5	22.73
Unsure	12	12.00	1	9.09	2	7.69	7	17.07	2	9.09
Other combination of Skin examination and/or blood test and/or patch test and/or review of medical history	12	12.00	0	0.00	5	19.23	3	7.32	4	18.18
Skin examination and review of medical history	11	11.00	0	0.00	3	11.54	4	9.76	4	18.18
Diagnostic tests	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Skin examination only	14	35.90	13	31.71	28	47.46	23	39.66	18	42.86
Skin examination, blood test, patch test and review of medical history	10	25.64	9	21.95	15	25.42	14	24.14	10	23.81
Unsure	4	10.26	8	19.51	4	6.78	7	12.07	5	11.90
Other combination of Skin examination and/or blood test and/or patch test and/or review of medical history	6	15.38	6	14.63	6	10.17	9	15.52	3	7.14
Skin examination and review of medical history	5	12.82	5	12.20	6	10.17	5	8.62	6	14.29

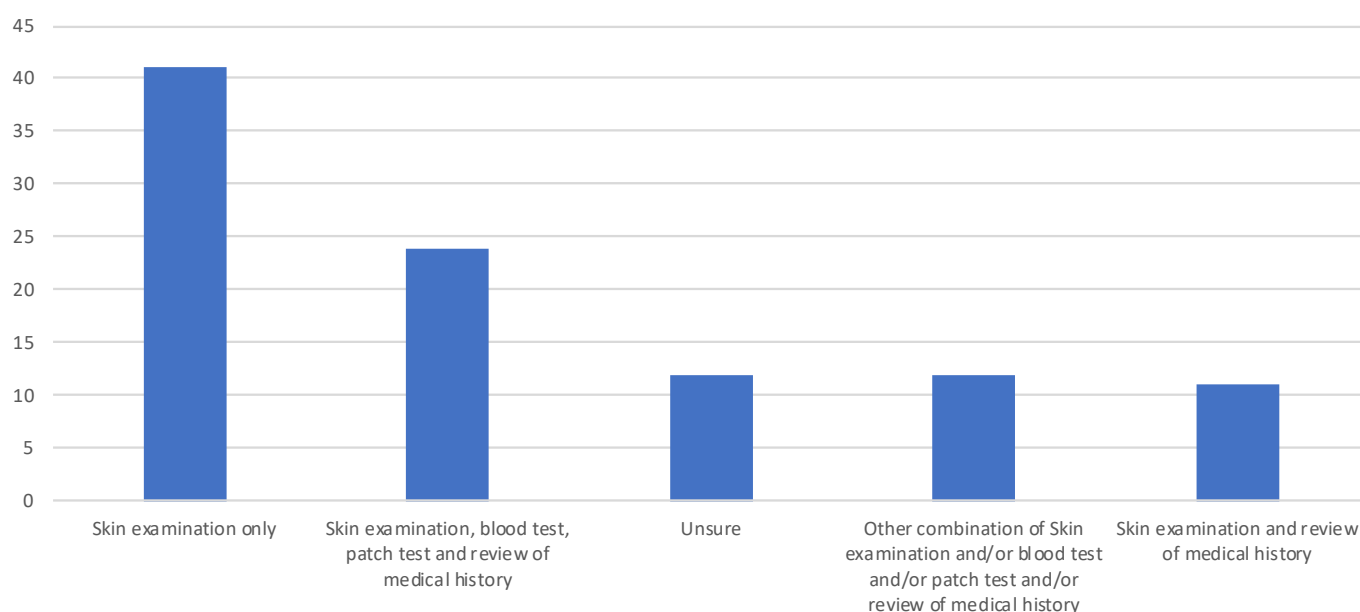


Figure 3.2: Diagnostic tests

**Support at diagnosis**

In the questionnaire, participants were asked whether they felt supported at the time of diagnosis. There were 64 participants (64.00%) that noted they had no support and this was the most common response followed by having some support, but not enough (n=21; 21.00%) and having enough support (n=15, 15.00%).

There were a number of sub-group variations. Participants with mild AD reported having no support more frequently than the general cohort (81.82% compared to 64.00% in the general cohort). Participants with moderate AD reported having enough support less frequently than the general cohort (3.85% compared to 15.00% in the general cohort).

Table 3.3: Support at diagnosis

Support at diagnosis	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=42)		Very Severe Atopic Dermatitis (n=22)	
I/we had no support	64	64.00	9	81.82	17	65.38	24	58.54	14	63.64
I/we had some support but it wasn't enough	21	21.00	0	0.00	8	30.77	8	19.51	5	22.73
I/we had enough support	15	15.00	2	18.18	1	3.85	9	21.95	3	13.64
Support at diagnosis	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
I/we had no support	27	69.23	24	58.54	40	67.80	39	67.24	25	59.52
I/we had some support but it wasn't enough	8	20.51	11	26.83	10	16.95	12	20.69	9	21.43
I/we had enough support	4	10.26	6	14.63	9	15.25	7	12.07	8	19.05

**Genetic and biomarker tests**

Participants were asked whether they had ever had a discussion about genetic tests or tests to see if there were biomarkers that might be relevant to their condition or treatment. The majority of participants (n=96; 96.00%) had not had a discussion while four participants (4.00%) stated they had had a discussion about this kind of test of which, two brought the topic up with their doctor.

Table 3.4: Genetic and biomarker tests

Biomarker/genetic testing (Discussions)	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
No one has ever spoken to be about this type of test	96	96.00	11	100.00	25	96.15	40	97.56	20	90.91
My doctor brought up the topic with me for discussion	2	2.00	0	0.00	0	0.00	1	2.44	1	4.55
I brought up the topic with my doctor for discussion	2	2.00	0	0.00	0	0.00	1	2.44	1	4.55
Biomarker/genetic testing (Discussions)	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
No one has ever spoken to be about this type of test	35	89.74	41	100.00	55	93.22	56	96.55	40	95.24
My doctor brought up the topic with me for discussion	2	5.13	0	0.00	2	3.39	1	1.72	1	2.38
I brought up the topic with my doctor for discussion	2	5.13	0	0.00	2	3.39	1	1.72	1	2.38



Participants were also asked about their interest in this type of test if it was available. The majority of participants (n=89, 89.00%) were interested in having it if it were available, three participants (3.00%)

indicated that they paid for this test themselves while eight participants (8.00%) indicated that they were not interested in this type of test.

Table 3.5: Interest in genetic and biomarker tests

Biomarker/genetic testing (Experience)	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=42)		Very Severe Atopic Dermatitis (n=22)	
I have had this type of test and paid for it myself	3	3.00	0	0.00	0	0.00	1	2.44	2	9.09
I have not had the test but would like to	89	89.00	8	72.73	24	92.31	37	90.24	20	90.91
I have not had this test and am not interested in it	8	8.00	3	27.27	2	7.69	3	7.32	0	0.00
Biomarker/genetic testing (Experience)	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
I have had this type of test and paid for it myself	2	5.13	1	2.44	2	3.39	2	3.45	1	2.38
I have not had the test but would like to	35	89.74	35	85.37	54	91.53	53	91.38	36	85.71
I have not had this test and am not interested in it	2	5.13	5	12.20	3	5.08	3	5.17	5	11.90

### Understanding of condition at Diagnosis

Participants were asked how much they knew about their condition at diagnosis. The main theme in this section was that participants, or their parents, knew nothing or very little about their condition (n=45, 45.00%). There were 18 participants (18.00%) that described having some knowledge about AD and this was primarily due to having another family member who also had the condition. There were also 19 participants (19.00%) that commented that they have lived their whole life with AD and it is therefore the only way of life that they know.

There was one sub-group variation in relation to participants that have very severe AD who reported knowing about AD through other family members, more frequently than the general cohort (31.82% compared to 18.00% in the general cohort).

### Participant describes themselves or their parents knowing nothing about the condition

*I didn't know anything and my Mum wouldn't know anything because she never told me, and I had to figure out things for myself. I wasn't until I was 20 and went to the dermatologist that I got a bit more information, but she said to do things that I had already figured out myself just based on, I needed certain things that Mum washed like certain detergents Mum washed with, were, I knew that I couldn't use fragrant stuff, even from a young age I*

*figured that out without her. Only silver jewellery. Does that make sense? Participant 13*

*Not much at all, I just, I wasn't actually told what eczema was really. When I went to the doctor and to many other subsequent doctors, the term eczema's just been thrown around and associated with dermatitis or dry skin but no one's really explained to me how or why that's come about. Participant 67*

*It wasn't really a lot of questioning I was able to do at that stage and of course my Mum was ... she had no idea about anything and it was never in her family and so she just essentially trusted what the Doctors said and did what they said and yeah that was kind of it. Participant 91*

### Participant describes their parents having good knowledge about the condition and being able to learn more over time

*Yeah, I think I've gained a lot more awareness and understanding as an adult, and probably ... I've been gathering that information since my 20s, but really within the last few years, I've got a better understanding in some ways with some stuff that I didn't realise before. Participant 53*

*My parents really knew much about it like my Mum, I've asked her a couple of times. She's been an emergency nurse for 30 something years. I said to her, "Even before you had me was there much knowledge*



of it?" She always said. The only reason she knows as much about eczema she does because of me.

**Participant 83**

My Mum sort of managed me more than anything so all I know is that I was extremely uncomfortable, itchy all the time, and my skin was always raw sores. I got bullied quite excessively for having dry skin and redness all the time. It sort of continued through to adulthood quite severely and gotten worse as I've gotten older and I've had various diagnoses of different types of eczema as different symptoms pop up over the years. **Participant 90**

#### Participant/parents describes knowing little about the condition - only that they itched

At the time, when I was younger, just that it made me really itchy and that I wasn't allowed to itch it. That was about it. I know Mum used a calamine bath and stuff like that. I mean that's what I remember. I remember my hands and sort of- short nails I think I remember the most. I had to have short nails all the time. **Participant 14**

I didn't know a whole lot about it. I knew that I would get really itchy and I would sometimes bleed and it

was a very uncomfortable condition. That's all I really knew, there wasn't the ability to just jump on Google and look up what it was. I think the doctor explained a bit about what might trigger it but it was, it can sometimes be due to allergies and eczema can get worse depending on what time of year it is. If you're very hot that can impact. I think they recommended cold showers, cold baths to try and treat it. But yeah, there wasn't a whole lot of information out there that I remember. Just cream. **Participant 66**

Apparently, I was very unsettled. I would say it affected me quite a lot. I think my family knew about it. I never sort of "It's an itchy skin condition." It never really affected my life too much at that point, apart from the fact I had to wear long sleeves and long pants. I view that I was a bit different but it was never something bad in my head. It was like I just happen to have a good family and good friends and whatnot. That was it. It was just an itchy, I just have an itchy skin basically. **Participant 72**

Not a lot. Just that it was itchy. That just drove me crazy. You know. **Participant 93**

Table 3.6: Knowledge of disease at diagnosis

Knowledge of disease at diagnosis	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant/parents describes knowing nothing about the condition	45	45.00	3	27.27	12	46.15	21	51.22	9	40.91
Participant describes that - as an adult - they have lived with all their life (it is all they know)	19	19.00	4	36.36	4	15.38	9	21.95	2	9.09
Participant describes knowing something about the condition from seeing other family members with atopic dermatitis	18	18.00	1	9.09	2	7.69	8	19.51	7	31.82
Participant describes knowing a lot or their parents having good knowledge about the condition	12	12.00	2	18.18	2	7.69	6	14.63	2	9.09
Participant/parents describes knowing little about the condition - only that they itched	9	9.00	1	9.09	4	15.38	4	9.76	0	0.00

Table 3.6 (cont.): Knowledge of disease at diagnosis

Knowledge of disease at diagnosis	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant/parents describes knowing nothing about the condition	18	46.15	20	48.78	25	42.37	26	44.83	19	45.24
Participant describes that - as an adult - they have lived with all their life (it is all they know)	5	12.82	3	7.32	16	27.12	12	20.69	7	16.67
Participant describes knowing something about the condition from seeing other family members with atopic dermatitis	8	20.51	8	19.51	10	16.95	9	15.52	9	21.43
Participant describes knowing a lot or their parents having good knowledge about the condition	1	2.56	4	9.76	8	13.56	5	8.62	7	16.67
Participant/parents describes knowing little about the condition - only that they itched	4	10.26	4	9.76	5	8.47	5	8.62	4	9.52

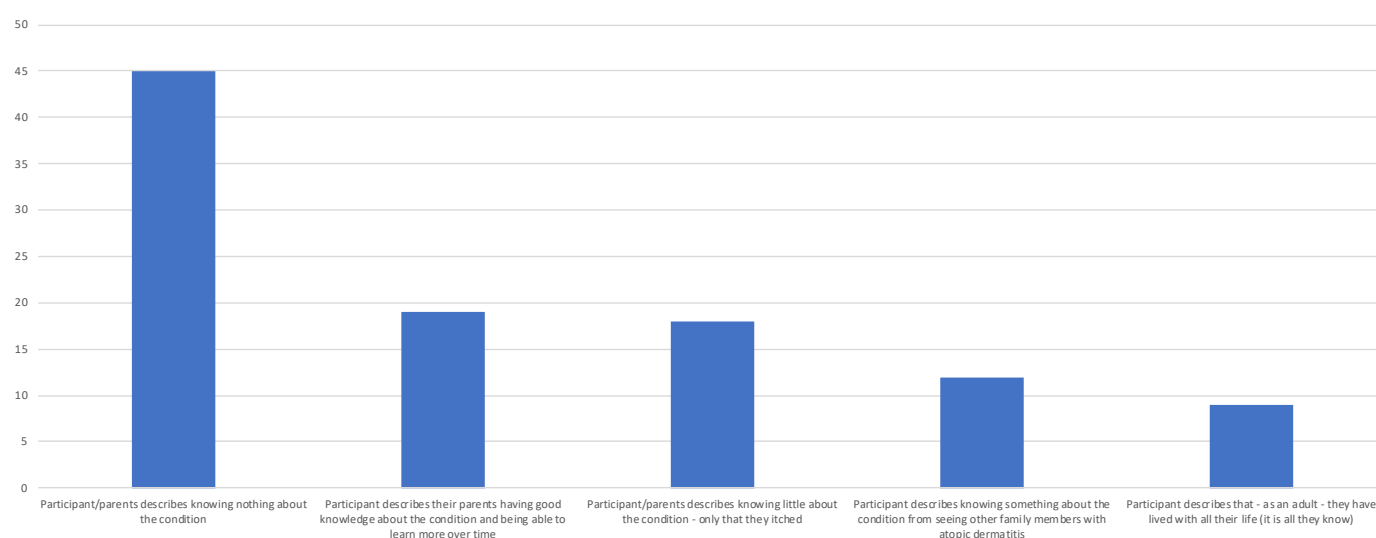


Figure 3.3: Knowledge of disease at diagnosis

### Communication and understanding of prognosis

Participants were asked whether anyone talked to them about prognosis. Over half of the participants (n=54, 54.00%) described that they understood that AD was a lifelong condition and did not expect it to get better:

*Given that I've had it for 57 years, I don't think it's going to get any better. No, and supposed to having spoken to both the GP and the dermatologist that I see from time to time, they both say it tends to get worse post menopause, so I'm thinking that it's not going to get any better. **Participant 44***

*No. I've been told all along my years, it'll change when you reach puberty, it'll change when you have*

*children, it'll change ... Everything. It has changed. It's changed in that it really flares up, rather than that it doesn't flare up. When I was a child, it used to flare up behind my knees, in my arm ... Inside of my elbow, my neck, and my eyelids, there were my flare ups. I used to get them in spots, and as a teenager I got ringworm like eczema. All up my arms, up my legs, on my buttock, my back, sometimes on my tummy ... I used to have this one particular spot on my tummy, always on my neck, and always around my mouth. When as an adult, less on my legs, just more around my arms, my hands, my neck, and my face. My face gets hit. My face and my neck get hit the worst. And now it's the hands, arms, neck and the face. And I used to get, actually, in my hair, on my genital area. There hasn't been a spot that hasn't had it. **Participant 61***

Anyway they told me I was going to grow out of it. "Oh, you'll hit 18 you'll grow out of it, you'll grow out of it." Well, 46 and still haven't grown out of it the days when it's great it's like, "yay". The days it's not I just want some of-- my prescription may tell me it's-- I'm a corticosteroid responsive dermatosis, critical crouch area, yes 20 to 30% of the body surface.

**Participant 64**

There were 22 participants (22.00%) that noted that they did not have a clear prognosis and these participants also spoke about the uncertainty of their situation:

Right now, I'm going through an episode. I don't know if it's because of the heat or - I'm pretty stressed. What was the other question? It's been with me throughout my life, but like I said, there was this period in my life where-- there were years where I didn't have any flare ups and I was completely fine. I don't need any steroids or anything like that. I'd say, since I was eight years old I've had it on and off. There's key times in my life where I feel like it flared up, just when I didn't... when I was 18, during uni... Yes. I think probably, another episode I had was in my mid 20s and then when I had kids, is when it reoccurred again. **Participant 15**

No. They've never said anything like that. They just give me the cream. **Participant 69**

No, that's what I'd like to know. Yeah, I'd like to know, I didn't think I'd ever feel like this. You know, I never

had a pimple or a blemish. Never had a pimple in my life, and I've never been on so much medicine and stuff now, since I've turned over 50, with that change of life. **Participant 93**

No doctor has ever, just to be straight, no doctor has ever been helpful, like ever, not that I can remember. They've never said anything. They always just say like, "We don't know why people get eczema." And they give you a lot of cortisone cream which I don't really like continuously using and actually the cortisone cream really seem to have very minor improvement just not much anyway. I just think I've got it for life and that I'm going to have to stay on the pill forever and I hope menopause maybe will make it go away [laughs]. I hope I don't have it forever but I just don't know why. I think it's hormonally related and maybe in menopause that will make it better, but then I think maybe it will make it worse. **Participant 99**

There were two sub-group variations. Participants with mild AD reported their prognosis as being something they will have for their lifetime less frequently than the general cohort (27.27% compared to 54.00% in the general cohort). Participants with very severe AD reported having their AD under control less frequently than the general cohort (4.55% compared to 18.00% in the general cohort).

Table 3.7: Understanding of prognosis

Understanding of prognosis	Total Participants (n=100)		Mild Atopic Dermatitis (n=11)		Moderate Atopic Dermatitis (n=26)		Severe Atopic Dermatitis (n=41)		Very Severe Atopic Dermatitis (n=22)	
Participant describes atopic dermatitis as something they will have for their lifetime and not necessarily get any better	54	54.00	3	27.27	16	61.54	22	53.66	13	59.09
Participant describes not having a clear prognosis	22	22.00	2	18.18	4	15.38	12	29.27	4	18.18
Participant describes their atopic dermatitis being under control	18	18.00	6	54.55	6	23.08	5	12.20	1	4.55
Participant describes expecting to be free of eczema in the future	6	6.00	0	0.00	1	3.85	1	2.44	4	18.18
Treatment conversations (Flares)	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes atopic dermatitis as something they will have for their lifetime and not necessarily get any better	24	61.54	23	56.10	31	52.54	36	62.07	18	42.86
Participant describes not having a clear prognosis	7	17.95	7	17.07	15	25.42	9	15.52	13	30.95
Participant describes their atopic dermatitis being under control	5	12.82	7	17.07	11	18.64	11	18.97	7	16.67
Participant describes expecting to be free of eczema in the future	3	7.69	4	9.76	3	5.08	3	5.17	3	7.14

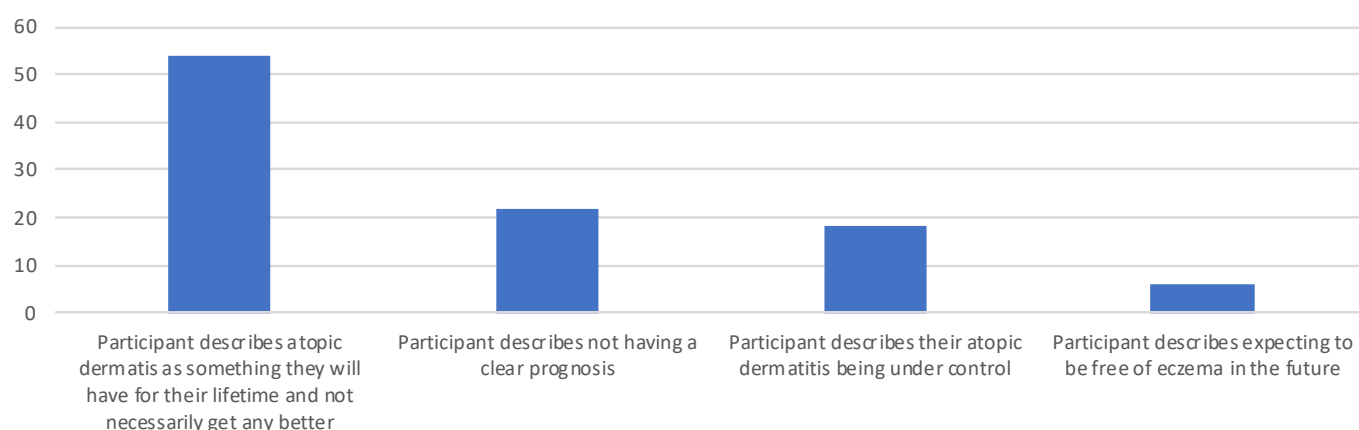


Figure 3.4: Understanding of prognosis