

Section 4 Decision-making

Section 4: Experience of health professional communication

Conversations about treatments

- Participants were asked to describe the conversations they have had about their AD in relation to treatment options. The main theme noted by 72 participants (72.00%) within this section was that participants felt that they were not really provided with options and that the majority of discussions focused on steroid cream.
- There was one sub-group variation. Participants with very severe AD described feeling as though there were no or limited treatment options more frequently than the general cohort (90.91% compared to 72.00% in the general cohort).

Decision-making

- Participants were asked who was involved in decisions made about treatment and care. Participants clinician and 5 The most common theme was that decision-making was primarily between the patient and their clinician (n=52, 52.00%). There were 37 participants (37.00%) that described also including their family in decisions while 32 participants (32.00%) spoke about decision-making as ultimately something they do on their own.
- There was one sub-group variation. Participants with mild AD reported decision-making as an individual thing more frequently than the general cohort (63.63% compared to 32.00% in the general cohort).
- Participants were asked about the things that they take into consideration when making decisions about treatment. The most common theme was that participants considered how much time the treatment would take to administer and this was noted by 34 (34.00%) of participants. There were 31 participants (31.00%) that described considering the severity of side effects, 30 participants (30.00%) spoke about understanding the evidence behind the treatment option, cost was another consideration that was noted by 27 participants (27.00%) and there also 19 participants (19.00%) that spoke about considering the long-term effect of treatment and how it will impact their overall health.
- There were three sub-group variations. Participants with mild AD reported considering the severity of side effects less frequently than the general cohort (18.18% compared to 31.00% in the general cohort) They also reported considering the treatment effectiveness/evidence base less frequently than the general cohort (18.00% compared to 30.00% in the general cohort). Participants that had a high school or trade education also reported considering the treatment effectiveness/evidence base more frequently than the general cohort (42.86 compared to 30.00% in the general cohort).
- Participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. The most common theme was that participants had changed the way they made decisions (n=31, 31.00%) and 24 participants described taking more of an active role or interest in their condition in adulthood.
- There was one sub-group variation. Participants with mild AD reported changes in the way they make decisions and becoming more informed, less frequently than the general cohort (18.18% compared to 31.00% in the general cohort).

Discussions about treatment

Participants were asked to describe the conversations they have had about their AD in relation to treatment options. The main theme noted by 72 participants (72.00%) within this section was that participants felt that they were not really provided with options and that the majority of discussions focused on steroid cream:

I would go to a dermatologist and they would, just give me cortisone creams, and stronger cortisone creams. And, was pretty much told that they manage it. And that there's no other options, really.
Participant 60

There aren't really any discussion. Just cortisone cream, then more cortisone cream.
Participant 69

Um, it's really just the steroid creams and avoid triggers, they don't spend too much time going through options, maybe because there aren't any?
Participant 72

Up until the last few years, the treatment I was aware of was just steroid creams. That was all I had used growing up. When, obviously, it wasn't so bad, I used steroids here and there, and it helped. I don't know what kind of available options there were because of the fact that I didn't really know anything more than steroids at the time. I guess in my childhood it wasn't bad enough to even go with Prednisone or anything. It was literally just the topical steroids. They weren't very strong at that point. I can't remember their names, but it definitely wasn't that strong at that point.
Participant 85

There was one sub-group variation. Participants with very severe AD described feeling as though there were no treatment options more frequently than the general cohort (90.91% compared to 72.00% in the general cohort).

Table 4.1: Discussions about treatment

Conversations about treatment	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 no treatment options as such, primarily one option (Steroid cream in particular)	72	72.00	8	72.73	17	65.38	27	65.85	20	90.91
Participant describes gentle washes/moisturising as part of their management regime	18	18.00	4	36.36	6	23.08	7	17.07	1	4.55
Participant describes being discussions about avoiding triggers	13	13.00	1	9.09	4	15.38	7	17.07	1	4.55
Participant describes being discussions about Alternative/Complementary Therapies	11	11.00	0	0.00	6	23.08	3	7.32	2	9.09
Participant does not recall discussions	11	11.00	1	9.09	3	11.54	6	14.63	1	4.55
Participant describes being discussions about wet dressings	10	10.00	0	0.00	2	7.69	3	7.32	5	22.73
Participant describes being given dietary advice (General, no dairy, no wheat/gluten, no citrus)	7	7.00	3	27.27	3	11.54	1	2.44	0	0.00
Participant describes being discussions about immuno-suppressants	5	5.00	0	0.00	3	11.54	2	4.88	0	0.00

Table 4.1 (cont): Discussions about treatment

Conversations about treatment	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/ Trade educated (n=42)	
Participant describes no treatment options as such, primarily one option (Steroid cream in particular)	28	71.79	35	85.37	37	62.71	44	75.86	28	66.67
Participant describes gentle washes/moisturising as part of their management regime	8	20.51	4	9.76	14	23.73	14	24.14	4	9.52
Participant describes being discussions about avoiding triggers	4	10.26	7	17.07	6	10.17	8	13.79	5	11.90
Participant describes being discussions about Alternative/Complementary Therapies	6	15.38	4	9.76	7	11.86	6	10.34	5	11.90
Participant does not recall discussions	2	5.13	1	2.44	10	16.95	4	6.90	7	16.67
Participant describes being discussions about wet dressings	6	15.38	3	7.32	7	11.86	5	8.62	5	11.90
Participant describes being given dietary advice (General, no dairy, no wheat/gluten, no citrus)	3	7.69	2	4.88	5	8.47	5	8.62	2	4.76
Participant describes being discussions about immuno-suppressants	2	5.13	1	2.44	4	6.78	1	1.72	4	9.52

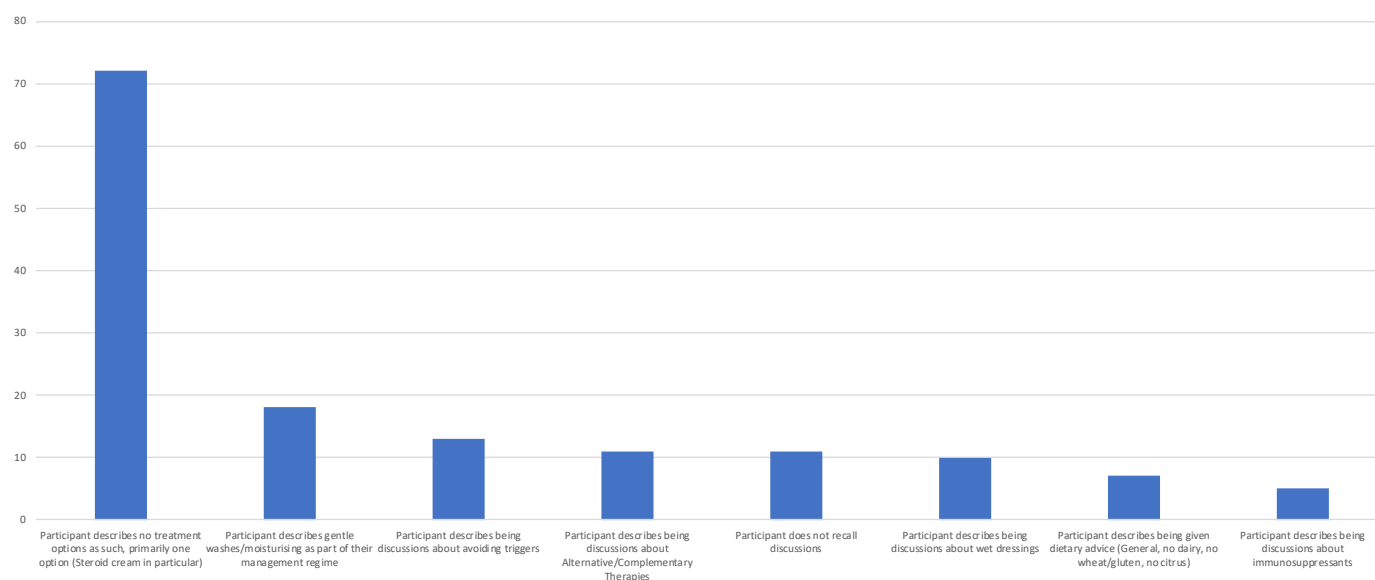


Figure 4.1: Discussions about treatment

Decision-making

Who is involved in decision-making

Participants were asked who was involved in decisions made about treatment and care. The most common theme was that decision-making was primarily between the patient and their clinician (n=52, 52.00%). There were 37 participants (37.00%) that

described also including their family in decisions while 32 participants (32.00%) spoke about decision-making as ultimately something they do on their own.

There was one sub-group variation. Participants with mild AD reported decision-making as an individual thing more frequently than the general cohort (63.63% compared to 32.00% in the general cohort).

Table 4.2: Decision-making process – who patients consult

Decisions about treatment	Total Participants		Mild Atopic Dermatitis		Moderate Atopic Dermatitis		Severe Atopic Dermatitis		Very Severe Atopic Dermatitis	
	n=100	%	n=11	%	n=26	%	n=41	%	n=22	%
Participant describes decision-making primarily with their clinician	52	52.00	6	54.55	15	57.69	21	51.22	10	45.45
Participant describes involving their family in decision-making	37	37.00	5	45.45	9	34.62	15	36.59	8	36.36
Participant describes decision-making as an individual thing (ultimately they make the decision)	32	32.00	1	9.09	7	26.92	19	46.34	5	22.73

Decisions about treatment	Anxiety/Depression		Regional/Rural		Metropolitan		University educated		High school/Trade educated	
	n=39	%	n=41	%	n=59	%	n=58	%	n=42	%
Participant describes decision-making primarily with their clinician	19	48.72	23	56.10	29	49.15	30	51.72	22	52.38
Participant describes involving their family in decision-making	14	35.90	14	34.15	23	38.98	17	29.31	20	47.62
Participant describes decision-making as an individual thing (ultimately they make the decision)	11	28.21	13	31.71	19	32.20	22	37.93	10	23.81

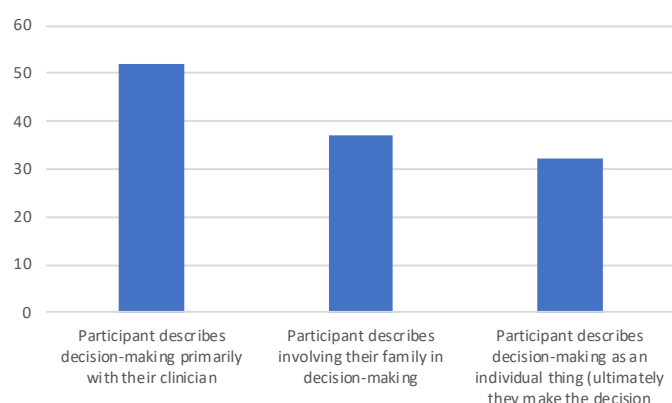


Figure 4.2: Decision-making process – who patients consult

What is considered when making decisions

Participants were asked about the things that they take into consideration when making decisions about treatment. The most common theme was that participants considered how much time the treatment

would take to administer and this was noted by 34 (34.00%) of participants:

Also, the practicality of applying things. One dermatologist would have put me on a regime which would basically, have meant I didn't do anything else 24 hours but treat my skin. Participant 20

*Definitely the practicality of treatment. if it's gonna have a big impact on the way we live our lives. We're an incredibly active family. Which I think also has a lot to do with the eczema, because I'm running here, there, and everywhere after three boys. But if it was something that was going to effect my ability to do that, or effect the types of food that I was eating, or was preparing. Or if I had to make a separate meal for myself, and then another meal for the rest of the family. Sort of things like that. **Participant 37***

*I'd say I take into account the upheaval it's going to cause. How convenient it's going to be for my lifestyle. **Participant 66***

There were 31 participants (31.00%) that described considering the severity of side effects, and this was largely referenced to how potential side effects may impact their quality of life:

Side effects is a big one. I'm quite active, I run my own business. I don't really have time to be sick. That would be the main thing really. What sort of side effects I get from it. **Participant 4**

I'd have to say, for me personally, side effects. Having had some disastrous side effects with a few things, of late. The potential side effects would be a big one for me, and as I seem to have very sensitive skin and be sensitive to lots of things, that's probably one of the things that would really make or break decisions for me. **Participant 8**

I guess maybe overall safety - I'm willing to take-participate in a trial but I'm sure like trials didn't get to a trial's stage needs to be quite safe but it would just be looking at things like...Actually, the doctor talked to last week said he'd been to a conference back in Eastern. He was saying that a recent study was saying that one of the side effects or adverse effects from long-term steroid use of more often overstated in it and it does actually interfere with patient compliance of creams because they're scared to use them for a long time for that reason that he was assuring me that, actually, from this day that they've found there's often more overstated. It ends up being detrimental to patients' treatment outcomes because too afraid to comply with using the cream for too long. Usually, it is stuff like that that I take into consideration. Is it something that's going to be too much with my life? Is there a big side effect or the potential for side effect? Is it more overstated than what's probably a realistic adverse effect or the chance of that happening. **Participant 63**

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Another key consideration for participants was the effectiveness of the treatment. This was noted by 30 participants (30.00%) and included understanding the evidence behind the treatment option:

Effectiveness. That's the only thing I take into consideration. How effective this is. Is this gonna be effective. **Participant 32**

Well, of course, I talk to the clinician about it and try and get the story about the treatment. Then I go home and I do quite a lot of research, but then, because I am a nurse, I will also talk to a couple of my friends who are quite interested in my skin. They're not bored the minute you open your mouth about it. My sister, who is quite intelligent, and loves research. I don't involve my husband, he has no interest at all in my skin. **Participant 70**

Pretty much nothing more than is it going to help. I'm not too fussy as far as I've got assurance that it's going to help. **Participant 85**

Cost was another consideration that was noted by 27 participants (27.00%). This was largely referenced to their current experience where the cost of treatments was often onerous:

For that light therapy thing, I was like, "Is that covered by Medicare?" Yeah that's it. I think it's just a cost thing. **Participant 21**

Cost. Because treatment just seems to get more and more expensive. **Participant 61**

Sometimes the price, the costs of stuff, because some of the ... I was using one cream that was very expensive, Elidel I think it was and then another...something or other that was another different kind of Cortisone that was ... Or a non-steroidal something that I had to get on a private script and that was quite expensive. It worked quite well but I didn't continue because it was so expensive, so the price can sometimes be part of it and convenience I suppose yeah. I am busy and lazy and so like I prefer a cream that I only have to put on once a day rather than twice per day, things like that, yeah those kinds of things. **Participant 68**

There were also 19 participants (19.00%) that spoke about considering the long-term effect of treatment and how it will impact their overall health:

*The biggest thing for me is that it's not, in the long-term, harmful to me as far as my overall health and well being goes. So definitely the long-term effects of something. Whether it's internal or external, on my skin. **Participant 18***

*When you open up the fine print in the box that you've been provided, with the drugs in it, it doesn't seem to always be consistent with what allergists, dermatologists, or GP's tells you. because I'm concerned with the long term use of cortisone, that's why. That's my major concern at the moment. **Participant 43***

Anything that I am deciding on, I need to know the long-term side effects of, especially if it's medication.

*If it's medication, I want to know the side effects and long-term side effects. **Participant 80***

There were three sub-group variations. Participants with mild AD reported considering the severity of side effects (18.18% compared to 31.00% in the general cohort) They also reported considering the treatment effectiveness/evidence base less frequently than the general cohort (18.00% compared to 30.00% in the general cohort). Participants that had a high school or trade education also reported considering the treatment effectiveness/evidence base more frequently than the general cohort (42.86 compared to 30.00% in the general cohort).

Table 4.3: Considerations when making decisions

	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 considering the time that the treatment will take to administer (whether there is a large burden, for example daily creams, baths and wet dressings)	34	34.00	3	27.27	10	38.46	13	31.71	8	36.36
Participant describes considering the severity of side effects and safety	31	31.00	2	18.18	6	23.08	14	34.15	9	40.91
Participant describes considering the effectiveness of the treatment and the evidence-base (which is often just trial and error)	30	30.00	2	18.18	6	23.08	14	34.15	8	36.36
Participant describes considering the cost	27	27.00	2	18.18	7	26.92	12	29.27	6	27.27
Participant describes considering the long-term effects	19	19.00	3	27.27	6	23.08	7	17.07	3	13.64
Effect on other people/family: how much they will be burdened	10	10.00	1	9.09	5	19.23	3	7.32	1	4.55

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes considering the time that the treatment will take to administer (whether there is a large burden, for example daily creams, baths and wet dressings)	15	38.46	11	26.83	23	38.98	18	31.03	16	38.10
Participant describes considering the severity of side effects and safety	11	28.21	14	34.15	17	28.81	21	36.21	10	23.81
Participant describes considering the effectiveness of the treatment and the evidence-base (which is often just trial and error)	11	28.21	13	31.71	17	28.81	12	20.69	18	42.86
Participant describes considering the cost	12	30.77	10	24.39	17	28.81	18	31.03	9	21.43
Participant describes considering the long-term effects	7	17.95	5	12.20	14	23.73	12	20.69	7	16.67
Effect on other people/family: how much they will be burdened	6	15.38	6	14.63	4	6.78	7	12.07	3	7.14

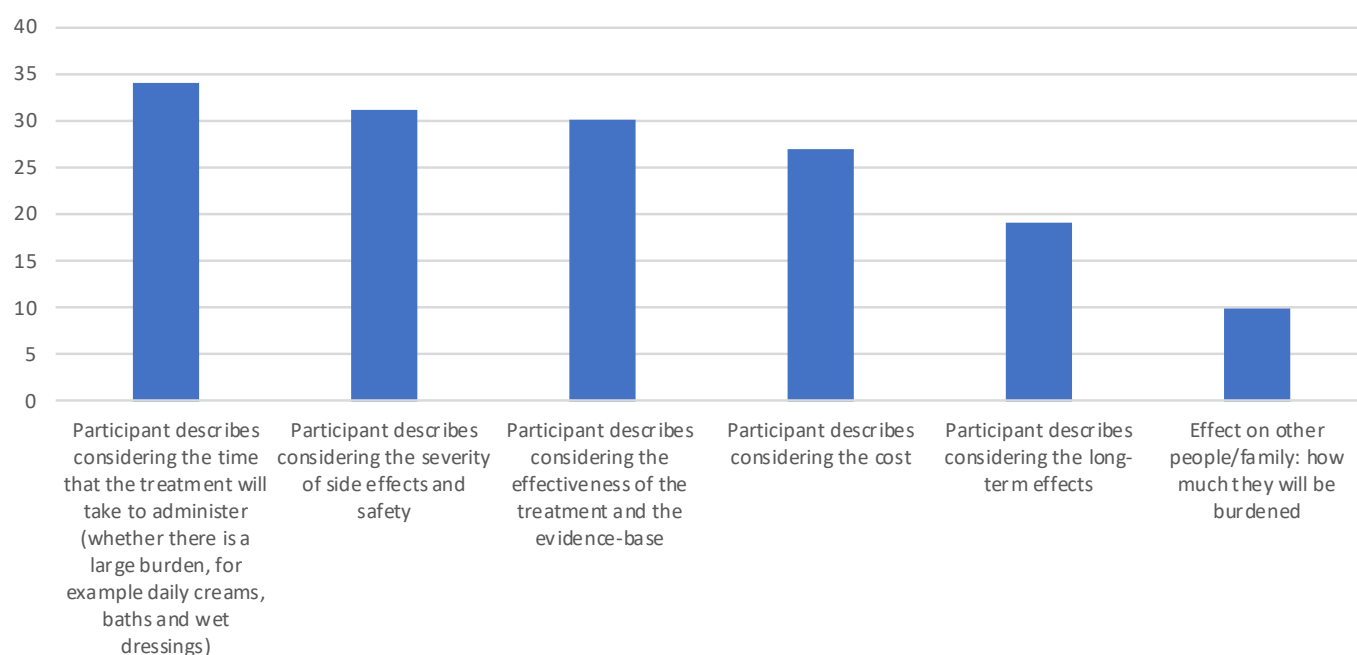


Figure 4.3: Considerations when making decisions

Changes in decision-making

In the final question about decision-making, participants were asked whether they felt the way they made decisions had changed over time since they were diagnosed. The most common theme was that participants had changed the way they made decisions (n=31, 31.00%) and this was primarily because they had become more informed and assertive:

*I think it has changed as I've gotten older. I think as I've gotten older, I'm less likely to just say yes to whatever is suggested. I'm a bit more likely to want to know the risks, the cost, the how long I'm gonna have to do it for, all those sorts of things. **Participant 33***

*Yes. Of course. I mean I've been an engineer for 20 odd years so obviously gaining that change of thinking and thought process. Yes, certainly. I'm a lot more evaluative and critical, shall I say? **Participant 41***

*I will do an awful lot of reading and research, and, of course, a lot of it has to be internet but I try not to use ridiculous sites. I try and use the sites that inform you. **Participant 70***

There were 24 participants that described changing the way they made decisions over time or as they got older. This also included taking more of an active role or interest in their condition in adulthood:

*Yes, definitely. It changes as you get older, doesn't it? It goes from being what your parents decided and then it's changed, especially because of what I do for a job, it's changed too. I have a bit more understanding and knowledge. **Participant 13***

*I think it's changed, over time. When I was, probably younger, and like, especially, teenage years, you and, you know, and when I was in my 20's, you're more vain, and worried about your looks, and your skin. And, whereas now, I'm more worried about my overall health. I'm more long-term, worried about my health, whereas when I was younger, I was more worried about my looks, and things like that. **Participant 60***

*I think they've probably changed over time especially probably for me that period of being 16, 17 up until probably 20 I was like Okay. It's not too bad. Hopefully, it'll disappear in the next couple of years. Probably, now that I'm 26 I'm getting to a point where this is actually getting really frustrating. I'm not getting frustrated with my doctors because I know they're doing what they know, but it's just frustrating. I'm getting frustrated with the whole situation. The way I question is now more how is this going to help me, when is this going to help me get rid of it effectively? **Participant 83***

A less common but notable theme was that participants felt that they needed to take decisions into their own hands, whether this meant seeking alternatives or deciding to no longer seek medical advice (n=13, 13.00%):

Yes, definitely. Definitely. but I feel like there's not enough talk about options outside of the drug world. We all know, there's no cure, right? At the moment. All we're doing, is we're trying to relieve our symptoms. Participant 43

I think perhaps after seeing the doctors the first few times, and probably being told the same things and not really being offered anything new, I guess that

affected my decision either to see a doctor. Participant 45

I suppose I was more eager to find out and try new things in the first place, but after so many failed attempts, I'm pretty over it. I just stick with steroids, because I know that that works. Participant 85

There was one sub-group variation. Participants with mild AD reported changes in the way they make decisions and becoming more informed, less frequently than the general cohort (18.18% compared to 31.00% in the general cohort).

Table 4.4: Decision-making over time

	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 a change in decision-making as they have become more informed	31	31.00	2	18.18	8	30.77	12	29.27	9	40.91
Participant describes no change in decision-making	24	24.00	4	36.36	6	23.08	9	21.95	5	22.73
Participant describes changes in life-stage which affected their decisions (getting older)	21	21.00	3	27.27	6	23.08	7	17.07	5	22.73
Participant describes needing to take decisions into their own hands (often because atopic dermatitis is dismissed by clinicians or they offer few solutions)	13	13.00	0	0.00	3	11.54	6	14.63	4	18.18
Participant describes a change in decision-making based on their experience	10	10.00	2	18.18	4	15.38	4	9.76	0	0.00

	Anxiety/Depression (n=39)		Regional/Rural (n=41)		Metropolitan (n=59)		University educated (n=58)		High school/Trade educated (n=42)	
Participant describes a change in decision-making as they have become more informed	13	33.33	14	34.15	17	28.81	16	27.59	15	35.71
Participant describes no change in decision-making	11	28.21	10	24.39	14	23.73	15	25.86	9	21.43
Participant describes changes in life-stage which affected their decisions (getting older)	10	25.64	9	21.95	12	20.34	14	24.14	7	16.67
Participant describes needing to take decisions into their own hands (often because atopic dermatitis is dismissed by clinicians or they offer few solutions)	3	7.69	4	9.76	9	15.25	7	12.07	6	14.29
Participant describes a change in decision-making based on their experience	2	5.13	1	2.44	9	15.25	6	10.34	4	9.52

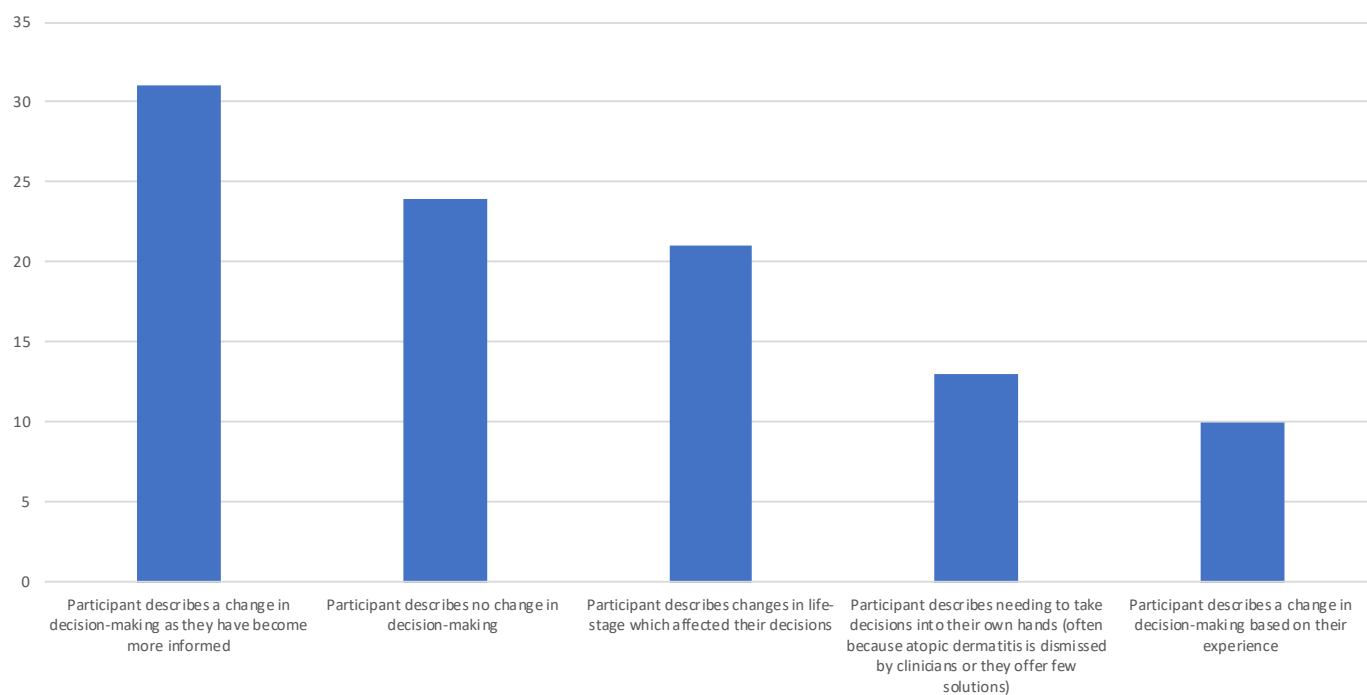


Figure 4.4: Decision-making over time