

Section 9 Expectations and messages

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

- When asked about their expectations of future treatment, there were a number of themes that emerged. The most common single theme (n=27, 27.00%) was that there should be a more holistic approach to treatment and this included access to different treatment options. There were two similar themes in relation to the expectation or hope that treatments would make the eczema go away (n=19, 19.00%) and that treatments would offer a cure (n=18, 18.00%). In relation to treatments that would make eczema go away, there was an underlying acknowledgement that eczema would always be part of the person's life. This differentiated the theme from treatments that would offer a cure where the hope or expectation was there, however the participants realised it was potentially unrealistic.
- There were 15 participants (15.00%) that described the expectation or hope that treatments would be affordable or less costly. The final theme noted by 15 participants (15.00%) was in relation to the severity of side effects. Participants described the expectation that treatments would be safe and not be detrimental to their long-term health.
- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were severe and uncontrolled itching and raw sensitive swollen skin from scratching, the least important sleep disturbance and sores that may become infected.
- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were safety of treatment/weighing up risks and benefits, severity of side effects and impact on quality of life. The least important were cost, ability to stick to treatment and including family in decision-making.
- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were quality of life and access for all patients to all treatments and services, the least important was economic value to government.

Expectation of future information provision

- Participants were asked what they would like to see in the future in relation to information provision. The most frequent theme was that participants would like information to be more available and easy to access (n=39, 39.00%). This theme included being able to know where to find information, which is not always obvious. There were 19 participants (19.00%) that were not able to provide recommendations on future information. Within these comments there was a sense of apathy that, because there were no cures or they did not think there were any advancements in treatments, there was little point in offering more information. Some of the specific topics that participants identified for future information provision were in relation to the causes of AD (n=10, 10.00%) and also how to identify and manage flares (n=10, 10.00%).

Expectation of future healthcare professional communication

- In relation to what participants would like to see improved in relation to the way that health professionals communicate with patients, the most frequent theme was the expectation that health professionals communicate with more compassion, empathy and to take their condition seriously (n=28, 28.00%). There were 20 participants (20.00%) that described the need for more accurate information and for health professionals to have more expertise in the field. An additional theme identified was that participants expect health professionals to listen to the patient, as they know their body best (n=14, 14.00%). This was followed by the expectation to have a care plan or structured follow-up (n=12, 12.00%) and finally, the expectation that health professionals should offer information about all treatments, medical and complementary (n=10, 10.00%).

Expectation of future care and support

- Participants were asked whether there was anything they would like to see in relation to the way the care and support they receive. There were two main themes identified including recommendations to develop opportunities to understand their condition, whether it is in relation to allergies, triggers or how to manage

their condition (n=18, 18.00%). The second main theme was the recommendation for specialist services, either a clinic or telephone support line that is accessible to people diagnosed with AD (n=13, 13.00%).

Messages

- Participants were asked what their message to people who make decisions about their condition would be. There was one main theme noted by over half of the cohort (n=56, 56.00%) where participants had the message that their condition should be taken seriously and that there is a need for compassion and to actively listen to patients. This included that their condition can be debilitating and that it is life-long. There were 34 participants that whose message was to treat the condition holistically, including emotional support, having a care plan and being told about treatment options. An additional 15 participants (15.00%) had the message that there needs to be more funding, not only for research but to develop health professionals to have more understanding and knowledge of the condition. The final theme was a message to consider the cost of treatments and financial burden patients often face (n=11, 11.00%).

Expectations of future treatment

Participants were asked a series of questions about their expectations for future treatments, information, health professional communication, and care and support.

When asked about their expectations of future treatment, there were a number of themes that emerged. The most common single them (n=27, 27.00%) was that there should be a more holistic approach to treatment and this included access to different treatment options:

For new treatments, I'd like to see the patient looked at holistically and the genetic testing is probably a good start with that. Looking at lifestyle, looking at even the climate in which there is like the holistic thing about everything about persons in the environment. Not just looking at it from a disease but looking at it skin tone from of something else. I don't know because I haven't been medically diagnosed with celiac. I get ignored up by doctors all at the time but I refuse to go back on the gluten. I don't get along with doctors very well on the eczema part of it. **Participant 19**

I'd like to see new research and new strategies coming out. I feel like the steroid creams and the wet dressings, they've been doing that for the last two decades, and I feel like they're still doing that. And there doesn't seem to be much movement there. So, I'd like to see new things being tried out, and maybe more research into the cause of it, and trying to find the root of where it stems from, and trying to treat it like that. I feel like a lot of the treatment now is just sort of putting a bandaids on it for the time being, rather than actually treating it long term. I'm not sure. I think they need to target more of a holistic perspective. Yeah, in terms of not just focusing on wet dressings, but looking at your diet and your lifestyle. And bringing that all together more. I feel like now-- ... things. **Participant 34**

I'd like to have a doctor after 30 years, plus 40 years probably going on now. I'd like to have a doctor that actually wants to approach it holistically, and would want to actually work on it like as a case, want to get to the bottom of it, or help me get to the bottom of it - That's a doctor who can listen to me and hear me and actually work on how can we approach treatment based on what you've told me, what we know. I'd also like to be heard and have a responsive doctor, what I feel is a responsive doctor to what they've heard. **Participant 99**

There were two similar themes in relation to the expectation or hope that treatments would make the eczema go away (n=19, 19.00%) and that treatments would offer a cure (n=18, 18.00%). In relation to treatments that would make eczema go away, there was an underlying acknowledgement that eczema would always be part of the person's life. This differentiated the theme from treatments that would offer a cure where the hope or expectation was there, however the participants realised it was potentially unrealistic.

Participant describes the expectation of treatments that make the eczema go away

Look, I get ... I'd probably like something that stops it from happening all together. I know it's probably an impossible dream but I guess, something that actually stops it from breaking out in the first place. So, that you don't actually get it. It would be good. **Participant 8**

A magic pill that I could take once a day and keep it all under-wrapped. Something that's quick and easy and-- (side effects, symptoms) I don't know how to say it. Don't want to have a \$70 cream for a small patch. My main thing is like the redness and dryness and when it goes scaly, my hands like flake. Man, it hurts obviously, to touch things and even bend my fingers. At the moment I've got formed slits across my knuckle and one of my fingers-- one of the finger beds. I've scratched everything in my sleep, I think and it's cracked on my fingertips. **Participant 12**

I think, oh, I, I don't know, with the solutions - ... that cover treatment. Okay. I mean, if there's this magic tablet, I could take every day, and not have any eczema, and, not have any other serious detrimental side effects to my body, then I would definitely take that every day - ... sorta thing. Yeah. Well - ... kind of. I, I just know, that there are different types of medications out there, that must, I don't know what they block, within your system, to help you, your skin improve. But the, you know, dermatologists say, we can, you know, this is the only thing that's gonna make your skin, really, you know, much better. But, I've - there's no way, I would go on something long term; like, they're long term with, with side effects. So, if there's - ... I'm happy to take something long term, as long as there's no side effects. ... and, yeah, if there's other magic creams out there, that can help, that would be great, or, things to stop me being itchy that, you know, other than antihistamines. 'Cause they're not always that great. **Participant 60**

Participant describes the expectation of a cure

What would I like to see from new treatment? Longer lasting effect. Because yeah. And not having to go ... Having to do something minimally, but with a longer effect. I'd love to see a cure, but - That'll be the day.

Participant 61

Something to completely cure it. Maybe if there was a vaccine or I don't know, something like that. Or just a really powerful ointment that would take it out within a week and not have to wait over a month or something like that....or something to just prevent it from ever happening. **Participant 75**

A cure would be good. I know a cure is not...they don't put the money on it... I've always said there are worst things in this world that you can have. Sometimes, you just need to take a step back and go "You know what actually this is actually kind of shit having eczema". I think something that just improves the quality of life would be nice. I'm not expecting that there's going to be a cure anytime soon but just something where I can at least manage it. I don't care if it's medication that I have to take. But I would prefer to not have use creams and to not have to be waking up in the middle of the night scratching or having the air conditioner on the whole day, cracking up my electricity bills because I just need to have it cold. It would be nice to be able to actually want to go to the beach, for once, and to not have to worry about what it's going to do to my skin. **Participant 83**

There were 15 participants (15.00%) that described the expectation or hope that treatments would be affordable or less costly. This was primarily referenced to the costs that they currently incur with their treatment:

I don't know. I don't know what I'd like to see. I think something that would just off it completely. Oh, cost-wise, definitely. You go and you get creams and I could go and spend \$50 at the chemist in a heartbeat, you

know? But it's a very ... Yeah, it's one of those things where you can drop quite a bit of money on it very easily. **Participant 2**

It is expensive, but I'm lucky in that, you pay the bill and off we go. For some who are on a pension or something, I could see this could be tricky. Although if you're on a pension, you get your medicines a lot cheaper anyway. **Participant 32**

It has been manageable obviously, but you got to spend your money on other stuff. I mean when you get a tube of ointment that costs \$40 every three or four weeks and moisturizers and special soaps and stuff and then antibiotics etcetera, etcetera. **Participant 41**

The final theme noted by 15 participants (15.00%) was in relation to the severity of side effects. Participants described the expectation that treatments would be safe and not be detrimental to their long-term health:

I think, oh, I, I don't know, with the solutions - ... that cover treatment. Okay. I mean, if there's this magic tablet, I could take every day, and not have any eczema, and, not have any other serious detrimental side effects to my body, then I would definitely take that every day. **Participant 60**

I would like to see more, preferably treatments that have less or no side effects in the long-term. I would like to see treatments that are more, that, for which doctors are more educated on so that they can actually impart some of that information to patients. **Participant 67**

Well, I'd like to see if they're going to design a tablet or something like that other one that I had, that you can take without being, you know, dangerous. Something like that. That you can just take these tablets on a regular basis and it keeps the skin clear. That's what I'd like to see them design. Because all the creams and the moisturisers, yeah, sure, you need moisturising, but the cortisone creams aren't good for you all the time. **Participant 93**

Table 9.1: Expectations of future treatment

| Expectations of future 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 the expectation of a more holistic approach to treatment | 27 | 27.00 | 2 | 18.18 | 11 | 42.31 | 9 | 21.95 | 5 | 22.73 | 10 | 25.64 |
| Participant describes the expectation of treatments that make the eczema go away | 19 | 19.00 | 5 | 45.45 | 4 | 15.38 | 7 | 17.07 | 3 | 13.64 | 6 | 15.38 |
| Participant describes the expectation of a cure | 18 | 18.00 | 1 | 9.09 | 5 | 19.23 | 8 | 19.51 | 4 | 18.18 | 8 | 20.51 |
| Participant describes the expectation of treatments to be of lesser cost | 15 | 15.00 | 1 | 9.09 | 3 | 11.54 | 7 | 17.07 | 4 | 18.18 | 8 | 20.51 |
| Participant describes the expectation of treatments having lesser or no side effects | 15 | 15.00 | 0 | 0.00 | 1 | 3.85 | 7 | 17.07 | 7 | 31.82 | 7 | 17.95 |
| Participant describes the expectation of treatments that reduce itchiness | 11 | 11.00 | 4 | 36.36 | 1 | 3.85 | 5 | 12.20 | 1 | 4.55 | 2 | 5.13 |
| Participant describes the expectation of reducing flares | 9 | 9.00 | 3 | 27.27 | 3 | 11.54 | 1 | 2.44 | 2 | 9.09 | 2 | 5.13 |

| Expectations of future treatment | Anxiety/Depression (n=39) | | Regional/Rural (n=41) | | Metropolitan (n=59) | | University educated (n=58) | | High school/Trade educated (n=42) | |
|--|---------------------------|-------|-----------------------|-------|---------------------|-------|----------------------------|-------|-----------------------------------|-------|
| Participant describes the expectation of a more holistic approach to treatment | 10 | 25.64 | 14 | 34.15 | 13 | 22.03 | 15 | 25.86 | 12 | 28.57 |
| Participant describes the expectation of treatments that make the eczema go away | 6 | 15.38 | 7 | 17.07 | 12 | 20.34 | 13 | 22.41 | 6 | 14.29 |
| Participant describes the expectation of a cure | 8 | 20.51 | 8 | 19.51 | 10 | 16.95 | 9 | 15.52 | 9 | 21.43 |
| Participant describes the expectation of treatments to be of lesser cost | 8 | 20.51 | 6 | 14.63 | 9 | 15.25 | 11 | 18.97 | 4 | 9.52 |
| Participant describes the expectation of treatments having lesser or no side effects | 7 | 17.95 | 6 | 14.63 | 9 | 15.25 | 9 | 15.52 | 6 | 14.29 |
| Participant describes the expectation of treatments that reduce itchiness | 2 | 5.13 | 3 | 7.32 | 8 | 13.56 | 7 | 12.07 | 4 | 9.52 |
| Participant describes the expectation of reducing flares | 2 | 5.13 | 2 | 4.88 | 7 | 11.86 | 3 | 5.17 | 6 | 14.29 |

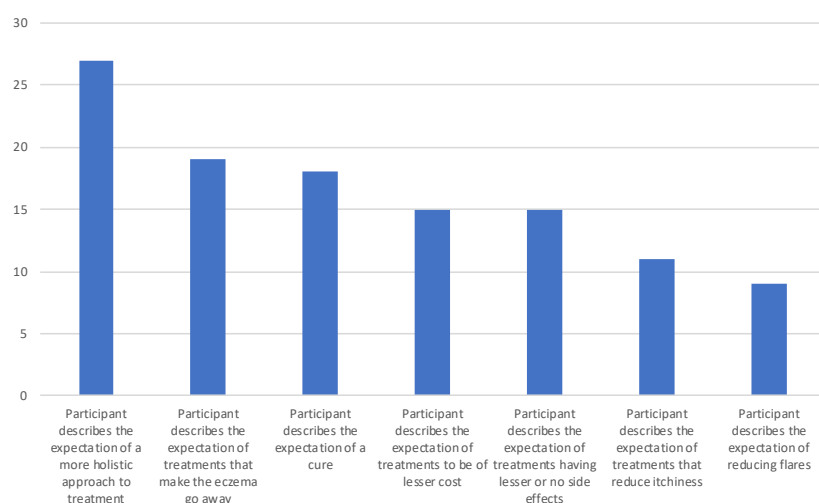


Figure 9.1: Expectations of future treatment (% of all participants)

Values when making decisions about treatment

Symptoms/aspects of quality of life important for treatments

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 10 is the least important. A weighted average is presented in Figure 9.2. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects reported were severe and not controlled

itching, and raw sensitive swollen skin from scratching; the least important were sleep disturbance and sores that may become infected. Figures 9.3 and 9.4 show the weighted rank by disease severity and location, the symptoms and aspects of quality of life are similar within sub groups for location. For disease severity, severe and uncontrolled itching is the most important aspect for all groups, and raw and sensitive skin the second most important for moderate, severe and very severe participant, while for mild this is less important than red patches and thickened skin.

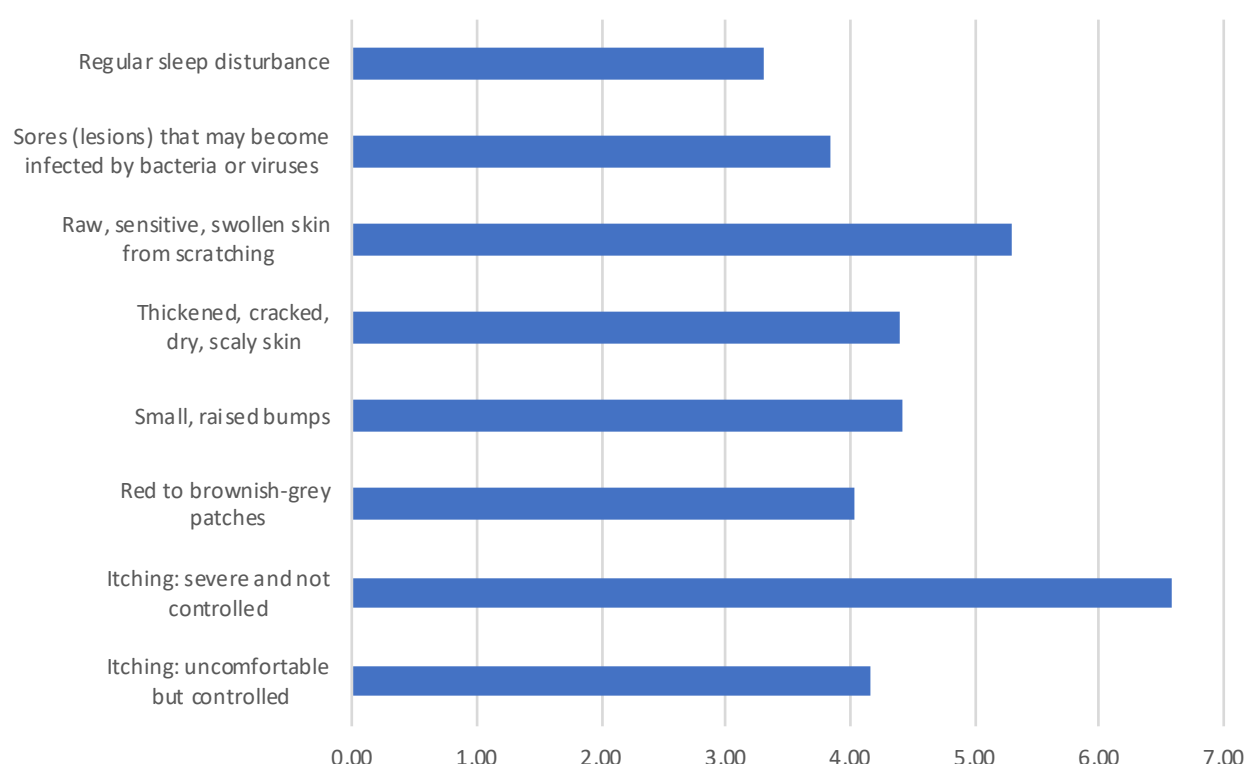


Figure 9.2: Symptoms/aspects of quality of life important for treatments all participants (weighted rank)

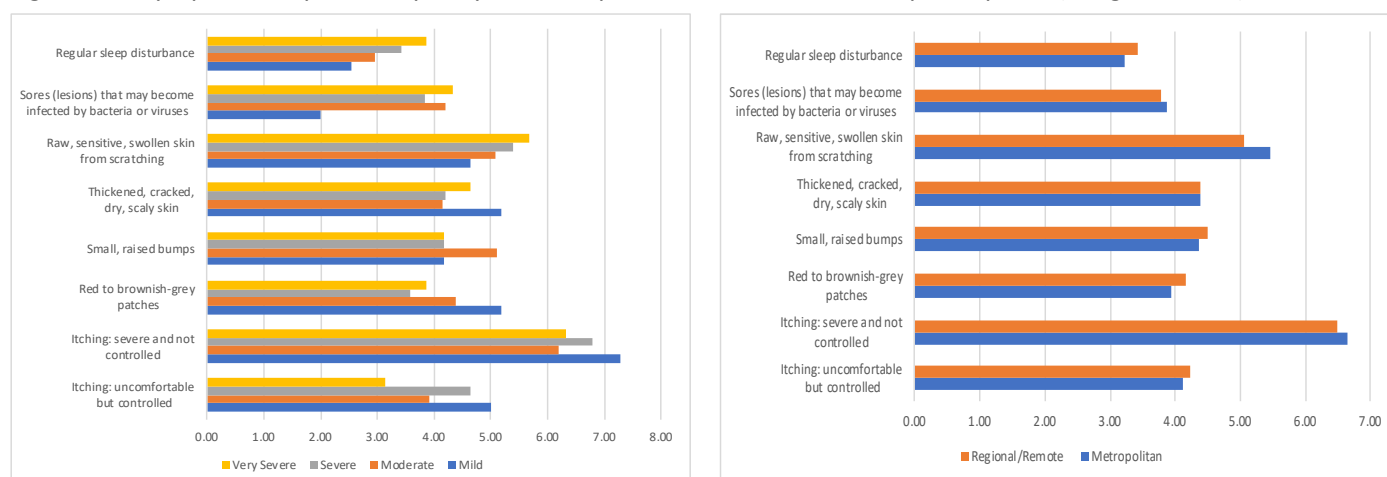


Figure 9.3: Symptoms/aspects of quality of life important for treatments by disease severity

Figure 9.4: Symptoms/aspects of quality of life important for treatments by disease class

Values that are important to patients when making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.5. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were safety of treatment/weighing up risks and benefits, severity of side effects and impact on quality of life. The least important were cost, ability to stick to treatment and including family in decision-making. Figures 9.6 and 9.7 show the weighted rank by disease severity and Location, the values for making treatment decisions are similar within sub groups and are similar to the overall cohort.

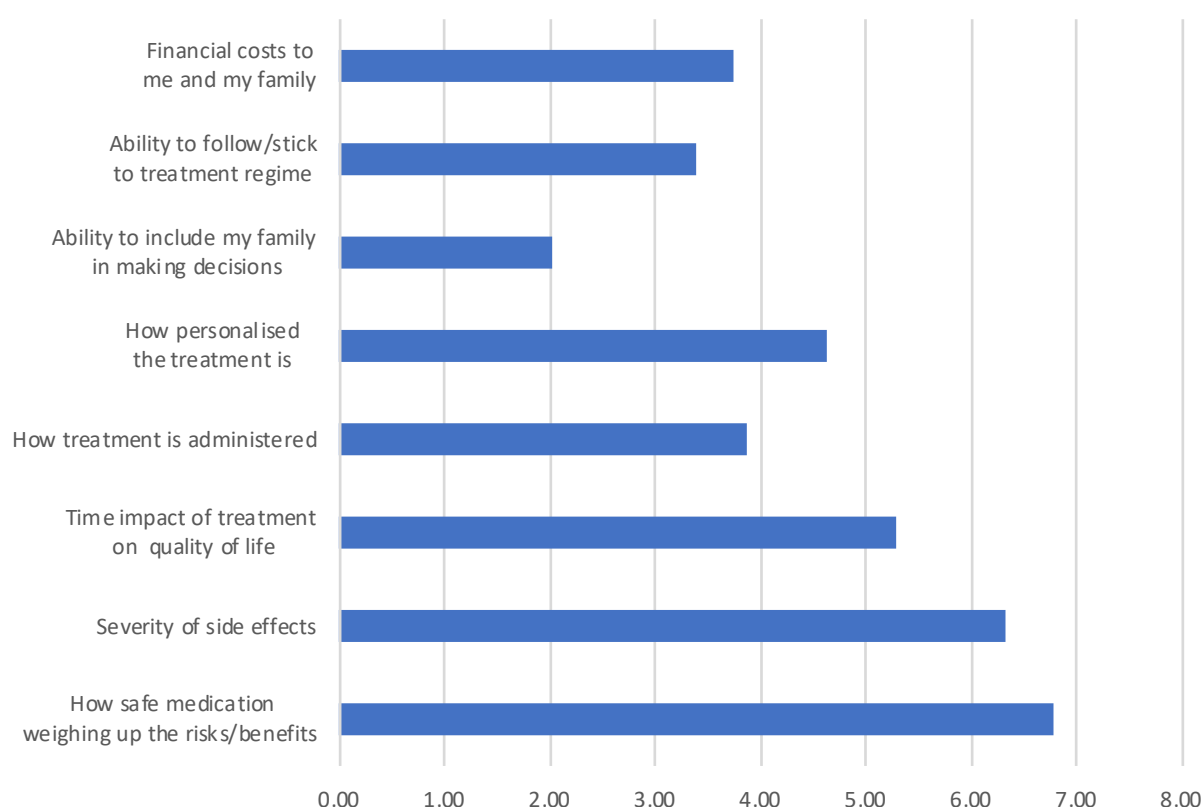


Figure 9.5: Values important when making decisions (weighted rank)

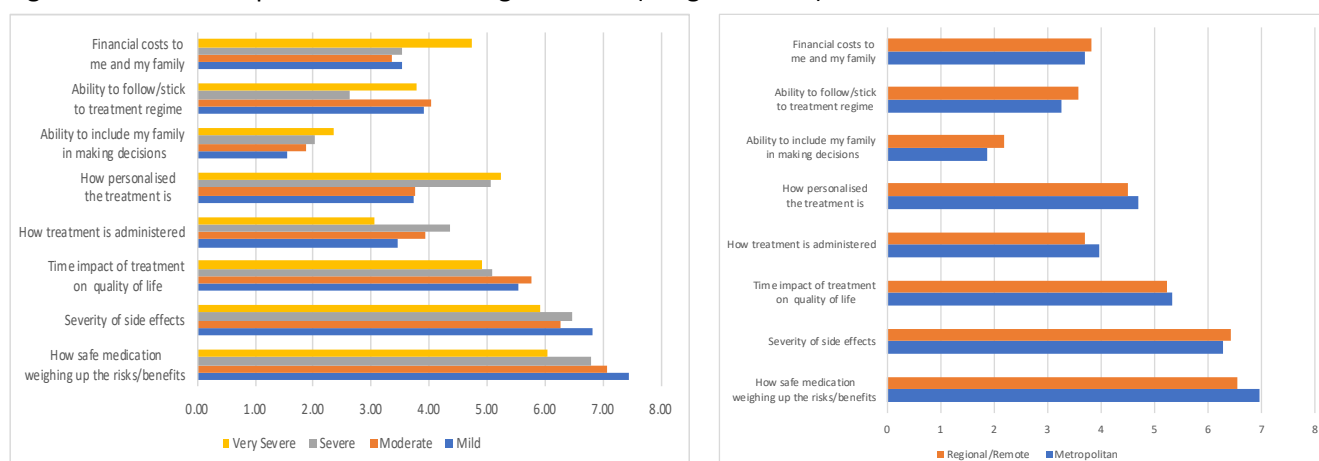


Figure 9.6: Values important when making decisions (by stage of disease)

Figure 9.7: Values important when making decisions (by location)

Values that are important to patients when others are making decisions on their behalf

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted

ranking, the higher the score, the greater value it is to participants. The two most important values were quality of life and access for all patients to all treatments and services, the least important was economic value to government. Figures 9.9 and 9.10 show the weighted rank by disease severity and location, the values for making decisions on their behalf are similar within sub groups and are similar to the overall cohort.

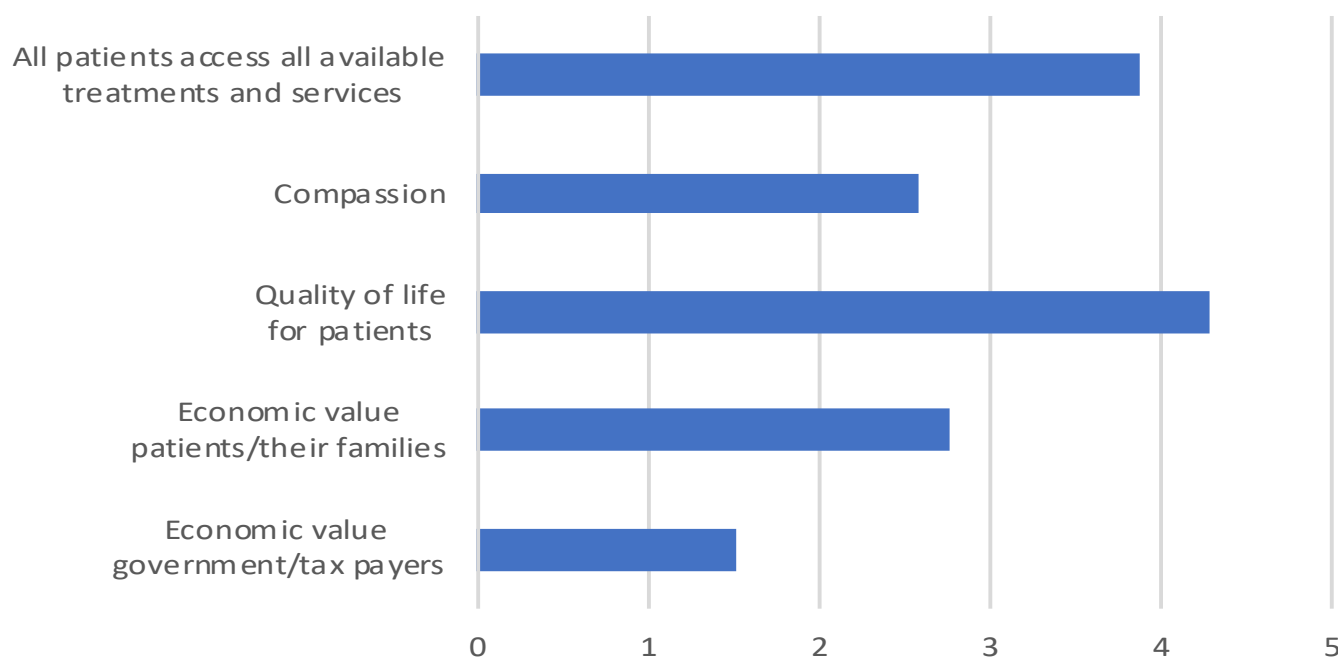


Figure 9.8: Values to consider on behalf of patients/families (weighted rank)

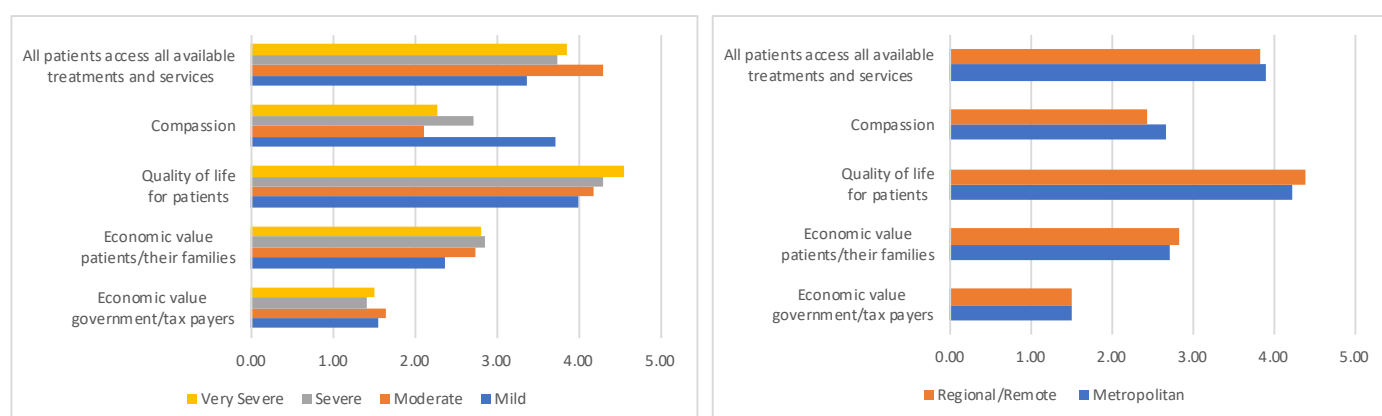


Figure 9.9: Values to consider on behalf of patients/families (weighted rank by disease severity)

Figure 9.10: Values to consider on behalf of patients/families (weighted rank by location)

Expectation of information provision

Participants were asked what they would like to see in the future in relation to information provision. The most frequent theme was that participants would like information to be more available and easy to access (n=39, 39.00%). This theme included being able to know where to find information, which is not always obvious:

It seems like there is not really a consistent source of good quality information that is easily accessible for everyday people, not well advertised, it maybe but I don't know about it. I would have liked to be taught things that are helpful before I had to figure them myself. I guess the public doesn't really...they just say, "You've got a bit of dermatitis" but they don't understand what it's like to have it all the time and for it not to go away. **Participant 13**

I don't think there was anything that wasn't covered but I think it would be good if there is research and there is things happening with eczema that would, if it was more known, cause I don't know about it. You don't see it mainstream. You have to look up things for it. In the chemist there might be a general brochure, or the doctor's, there might be a general brochure on what eczema is but more specific. Yeah, and what's being done. Is there any research or .. I've never heard of anything that's dramatically changed. **Participant 27**

I guess to be honest, I haven't really had much information given to me, other than orally from the GP. And just sort of spoken about things. I can't say that I've had ... I guess with the asthma, I've had information for asthma clinics, and the asthma nurse at the hospital where my son was diagnosed, and those sorts of things. But I haven't gone looking for that sort of information for eczema, so I don't know whether it's out there or not. But probably, simple things that you could do, to ease the eczema, or to ease the itch, or fabrics to avoid in clothing. Sort of things that sort of people are general knowledge in the eczema community for one of the better terms, are things that are likely to flare up eczema, that sort of, someone whose newly diagnosed might not know. So something like, the collective wisdom of people in Australia, of things that set you off. **Participant 37**

There were 19 participants (19.00%) that were not able to provide recommendations on future information. Within these comments there was a sense of apathy that, because there were no cures or they did not think

there were any advancements in treatments, there was little point in offering more information:

Not that I can think of. After all the bits and pieces that I've read over the years, I don't really think that there's too much more, unless that they find there's something new. I don't think there's too much more really. **Participant 2**

Well, I don't really know because I haven't really looked. Honestly, I really haven't and this is going to make me go on the computer tonight and have a look because I don't know that. Because honestly, I have never really looked at what other treatment is available other than cortisone cream. How crazy is that? **Participant 64**

That's a good question. No, probably not. I think this is where the one on one consultations are important because every condition is specific to a person and information on paper is quite generic so no, probably not. **Participant 71**

Some of the specific topics that participants identified for future information provision were in relation to the causes of AD (n=10, 10.00%) and also how to identify and manage flares (n=10, 10.00%).

Participant describes information about the cause of eczema

I find the doctors especially, they're all very just medication and cream-focused. I only learned about other things. I can do diet things, just from looking it up myself. Instead of just treating the problem, focusing on the cause and how to minimize the cause. **Participant 12**

Good question. I think some more research into the cause of it and then educating us what causes it. Because we're all told, "It could be hereditary. It could be environmental. It could be the food you're eating. It could be stress." It's so general. I don't know if that's also linked to the fact that there is no cure. They can't detect or pinpoint a cause. I know everyone is different. Yes, totally. Yes, definitely, yes. Some new information, some research into it. Some new facts, case studies, new findings. Yes, I would love to hear something new. **Participant 15**

Well, I feel like- I'm not using very particular terms with all of this and I feel like just even knowing what the common causes are for eczema. Usually you just go

online and it's just like a dry skin, but it isn't looked after and a lot of people just think oh you're just not moisturising enough, but it's a lot harder than that. So, I think that people who do have it can educate themselves and then educate other people as well, but just knowing the deeper causes of it, not just your given, it could be your family. It's like well, okay then what's the reason behind all that then too. So if it's in a gut health thing that's going on at all, whatever it might be so that, there's lots of reasons people have eczema in this world so. Yeah, so I think just even looking at the I think layers of the skin as well would be interesting, like as a diagram, just so we can see like whether it's just how deep it goes, if it is from the gut health and how that travels up to the skin. Cause isn't the skin like your biggest organ? **Participant 79**

Participant describes information about ways to identify flares or prevent flares or eczema in general

A format on how it's presented with a regime of how not to get it to flare up, the preventatives along with a care plan. **Participant 17**

I wouldn't say before the eczema gets really bad and it gets cracks and it's weeping or flaking or you got that

skin...there was things that happened prior to getting that bad that you might fail to notice. I think there needs to be some sort of "okay if you start feeling this on your skin or if you start seeing is this" - this is actually the action that you need to take straight away so it doesn't get to this point. There needs to be some sort of an action plan or I think to get more information per se so hopefully it can be some sort of specialist and attract somewhere that you just possibly go to a website and can go this is happening to my skin what can you say? The information out there because it is hard to find. Like you can google the stuff and there is lots of information out there but I think it tries to pigeonhole every person with eczema into a same box and I don't think you can. **Participant 55**

More accessibility the information would be great. And having it presented in a scientific way, but still fairly plain English style, easy to understand. More of a why does this happen than just a oh, it happens kind of format; because, yeah, I tend to find that they just say, "This is what happens. This is it", and they never explain why. So, I'd love to see a why, more of the reasons behind what we know about eczema and why it does what it does. **Participant 92**

Table 9.3: Expectations of information provision

| Expectations of future information provision | 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 information that is more available and easy to access | 39 | 39.00 | 1 | 9.09 | 12 | 46.15 | 14 | 34.15 | 12 | 54.55 |
| Participant describes not being able to recommend any additional information | 19 | 19.00 | 5 | 45.45 | 4 | 15.38 | 8 | 19.51 | 2 | 9.09 |
| Participant describes information about the cause of eczema | 10 | 10.00 | 0 | 0.00 | 3 | 11.54 | 2 | 4.88 | 5 | 22.73 |
| Participant describes information about ways to identify flare-ups or prevent flare-ups or eczema in general | 10 | 10.00 | 0 | 0.00 | 4 | 15.38 | 4 | 9.76 | 2 | 9.09 |
| Participant describes information about more holistic approaches to eczema | 6 | 6.00 | 5 | 45.45 | 0 | 0.00 | 1 | 2.44 | 0 | 0.00 |
| Participant describes information about adult eczema (including that there is a lot about childhood eczema) | 6 | 6.00 | 0 | 0.00 | 1 | 3.85 | 2 | 4.88 | 3 | 13.64 |
| Participant describes information about the side effects of treatments | 6 | 6.00 | 0 | 0.00 | 3 | 11.54 | 1 | 2.44 | 2 | 9.09 |
| Participant describes information about genes, genetic causes and hereditary links to eczema | 4 | 4.00 | 0 | 0.00 | 0 | 0.00 | 3 | 7.32 | 1 | 4.55 |
| Participant describes information about mental health and emotional support | 4 | 4.00 | 0 | 0.00 | 1 | 3.85 | 2 | 4.88 | 1 | 4.55 |

| Expectations of future information provision | Anxiety/Depression (n=39) | | Regional/Rural (n=41) | | Metropolitan (n=59) | | University educated (n=58) | | High school/Trade educated (n=42) | |
|--|---------------------------|-------|-----------------------|-------|---------------------|-------|----------------------------|-------|-----------------------------------|-------|
| Participant describes information that is more available and easy to access | 16 | 41.03 | 19 | 46.34 | 20 | 33.90 | 18 | 31.03 | 21 | 50.00 |
| Participant describes not being able to recommend any additional information | 8 | 20.51 | 7 | 17.07 | 12 | 20.34 | 13 | 22.41 | 6 | 14.29 |
| Participant describes information about the cause of eczema | 2 | 5.13 | 5 | 12.20 | 5 | 8.47 | 6 | 10.34 | 4 | 9.52 |
| Participant describes information about ways to identify flare-ups or prevent flare-ups or eczema in general | 4 | 10.26 | 5 | 12.20 | 5 | 8.47 | 6 | 10.34 | 4 | 9.52 |
| Participant describes information about more holistic approaches to eczema | 0 | 0.00 | 1 | 2.44 | 5 | 8.47 | 4 | 6.90 | 2 | 4.76 |
| Participant describes information about adult eczema (including that there is a lot about childhood eczema) | 3 | 7.69 | 4 | 9.76 | 2 | 3.39 | 5 | 8.62 | 1 | 2.38 |
| Participant describes information about the side effects of treatments | 1 | 2.56 | 3 | 7.32 | 3 | 5.08 | 5 | 8.62 | 1 | 2.38 |
| Participant describes information about genes, genetic causes and hereditary links to eczema | 2 | 5.13 | 1 | 2.44 | 3 | 5.08 | 2 | 3.45 | 2 | 4.76 |
| Participant describes information about mental health and emotional support | 2 | 5.13 | 3 | 7.32 | 1 | 1.69 | 2 | 3.45 | 2 | 4.76 |

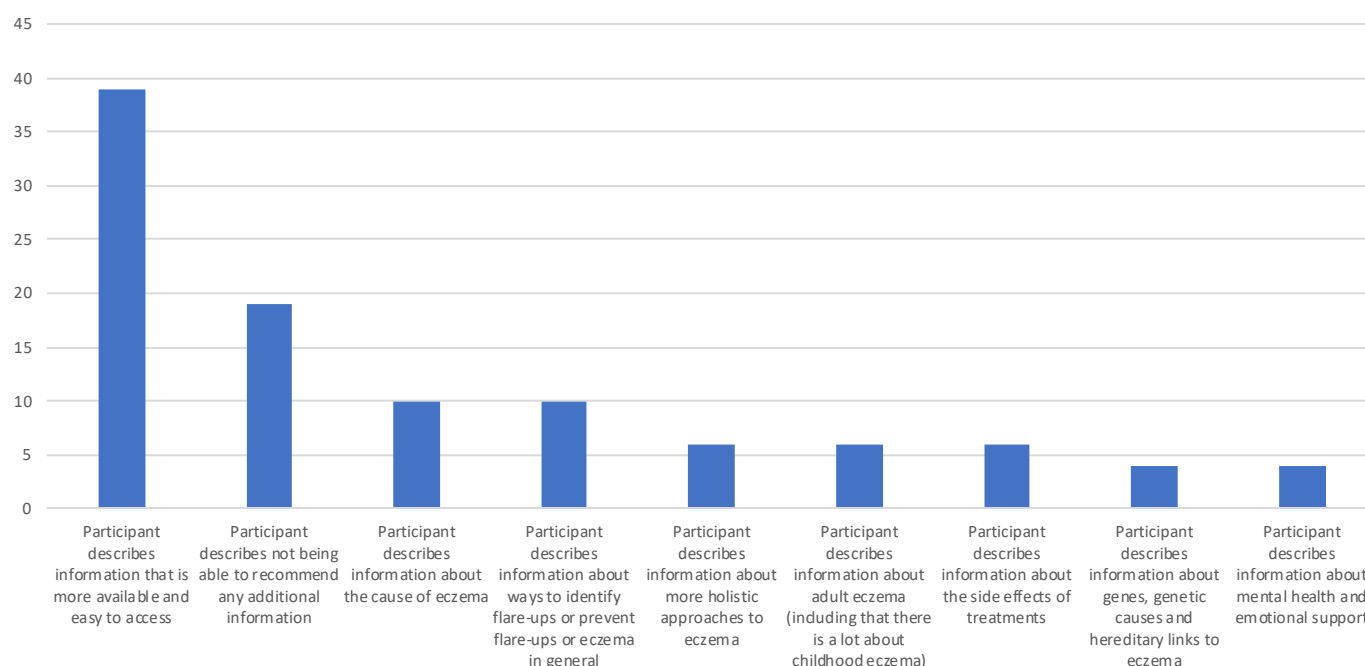


Figure 9.11: Expectations of information provision (% of all participants)

Expectation of health professional communication

Participants were asked whether there was anything they would like to see improved in the future in relation to the way that health professionals communicate with patients. The most frequent theme was the expectation that health professionals communicate with more compassion, empathy and to take their condition seriously (n=28, 28.00%). There were 20 participants (20.00%) that described the need for more accurate information and for health professionals to have more expertise in the field. An additional theme identified was that participants expect health professionals to listen to the patient, as they know their body best (n=14, 14.00%). This was followed by the expectation to have a care plan or structured follow-up (n=12, 12.00%) and finally, the expectation that health professionals should offer information about all treatments, medical and complementary (n=10, 10.00%).

Participant expects health professionals to be compassionate/empathy/take eczema seriously.

Yes. I feel like I'm just nitpicking if I say that they don't understand how life-limiting it can be. Sometimes you feel like they're just, "Oh, you're a bit itchy." They don't really understand that it's quite disabling. Yes, they don't understand how serious it can actually get. Particularly if sometimes your skin's itchy and it doesn't show up as really red. Sometimes you can get the eczema that's pretty much invisible but it's still just feels like 10 million mosquito bites. [laughs]. It feels like, "Oh,

what?" Yes. (It's definitely not nitpicking) Yes, that's it. Participant 42

I think just sort of not very condescending. So, being a little bit less condescending and appreciating that you're experiencing something that is making your life difficult and it's frustrating, and you want help. But I think, yeah, I think a bit of bedside ... I think really good interpersonal skills and some empathy would be good. And being careful not to just step into that patient/doctor role of, "I'm just gonna bully you because you're my patient and I'm the expert and you just have to do this. I'm actually not offering you any alternative." Yeah, a bit more collaborative as to how you can come up with, I don't know, a way of managing things. Participant 53

Yeah, definitely I think health professionals need to have a level of care and empathy, and support. It tends to be missing from a lot of male doctors that I've seen. That's completely lacking from their treatment. With that comes other things. If you're lacking empathy, and you already have this belief, or this knowledge that conflicts with what you're saying, then you're immediately ... Even if there's all this fantastic information, or new information presented, because of their lack of empathy and their large egos, they just ... It just goes in one ear out the other, so they don't really give you much credibility. You are in a position where you feel like you need to justify a lot of stuff, and you need to do more work to get them to actually give you the care that you're after. Yes, I think a level of support and empathy, and maybe smaller egos would be great. Participant 91

Participant expects more accurate information about eczema/education about eczema for health professionals so they are better equipped to explain eczema.

*Look, I think probably one of the things I think is sadly lacking across a lot of GP's is probably even just education around eczema, what it is and how it affects people. I think they tend to be a bit blasé and maybe I would be too if I saw 20 people a day with eczema rashes. I might be a bit more blasé about what you say or what you give people. I think it's probably GP's are not particularly well-educated sometimes around eczema and eczema conditions. **Participant 8***

*It's hard, and I haven't really necessarily been in that for a while, but I would just like to know that they're updated with all of their information, so they actually have everything on hand. Sometimes I trust myself more than I trust them and that's not right. Yeah, right so I'd love to have the confidence that they're attending to it, as it is a really serious issue. **Participant 54***

*Yes, perhaps a better recognition of what is just the standard eczema and what's getting quite an extreme eczema that's affecting people and really starting to affect them in their day-to-day lives. I really don't feel like anyone's been rude or written me off or not taking me 100% seriously. I'm sure that they have, but just perhaps failing to recognize that it's becoming a bigger issue than what it is. I don't know whether part of that might have been...I don't want to blame everybody else because part of that's probably my fault for a few years where I've just gone, "Ah, what's the point in saying it because nothing else is going to change?" But it might be nice if people didn't get to that point and feel like there's no reason to go to the doctor because they're not going to tell me anything new that I don't already suspect they're going to tell me. **Participant 63***

Participant expects health professionals to listen to the patient, as they know their body best/more time.

"I think it's probably more about, being a bit open minded. You know, I've definitely found that, because they just seemed to be focused on this type of treatment is the only treatment that works. And, actually seeing that there is actually other ways of treating somebody. Because, it is diet. It is your psychological state. It is whether you're exercising or not. It is your family and friends support group and all those things. You know, when they're talking to us I think it would be more helpful to touch base on that. What else are you doing? Is there anything else that,

*you know Would you like some information? Or, you know, have you tried this? Or, this is the best that I know. Even actually putting it out there, is there a list of people in our area. You can, probably someday, you could do yourself through the eczema association. You should find out. But, this is a great get together, you know, once a week, here's their number." **Participant 18***

*Hugely. Again looking at it holistically not looking at it as skin disease. Looking at it from a whole body perspective and the whole environment perspective. From a whole body is, I'm talking about diet, habitat, stressors in the environment all of those things. I didn't know how to tell this story but it's always stuck in your mind and I'd love to have these stories told somewhere. I've had stress in eczema. **Participant 19***

*Yes, I'd like to see them do a longer consult, but I know that's not going to happen (laughs). Yeah, eczema is so complex. It's really hard, you know with six minute meetings at the GP, it's a really hard thing to deal with. I can't expect the GP to explain it properly to me in six minutes or outline all the possible treatment options. And I think that sometimes that the GPs, no, got a rash, here's the steroid cream. That's what they write the script for and you're out the door. So, I'm not too sure that even the GPs are actually highly up with how eczema should be monitored. And where to, if there steroid creams aren't actually working or you've been on them for too long, where to from here. I'm not too sure that they understand what to do with that. **Participant 65***

Participant expects to have a care plan or some type of follow-up.

*Well, it would be so good-- I don't know if they do this or whether my doctors just haven't done it, but my son has an asthma plan. Why can't they do like an Eczema plan? Like, "In the days they flare-up, do this." Something like that would be really good. A management. Yes. **Participant 12***

*I think there just needs to be a greater understanding from health professionals about eczema, because I feel like they disregard it as a serious condition. I feel like they really need to develop some action plan, a long-term action plan rather than just providing a quick fix steroid cream. Were somebody can be on steroid cream in five years or something, because that's all that's ever been given. I feel they need to really take it seriously and treat it as a serious condition, because it is. **Participant 38***

*Yeah. So a follow-up would be good. When you go in for eczema, especially with a GP, because that's what I think everybody at this point call. When you go in to prove the GP, I think they should explain how eczema works. That it is an individual experience and that you're going to go through different things of trial and error to trial, and it's not necessarily going to work. And then follow up to see if things have worked, and calling to see what the next step to take. There's a lot of... I've given up at different points, and I think a lot of people have felt the same that go to the GP who will prescribe this. It works for bit, stops working, and then you just go, "I'm not going to go because nothing's going to work." **Participant 61***

Participant expects health professionals to provide information about all treatment alternatives, including both medical and complementary treatments.

Personally, they should try and get to the root cause of eczema for the just fixing the sort fixing like the symptoms on top of it. Also asking them if they want to take alternative treatments. Obviously, the medication they're going to provide and to not going to fix it but there is other things that you can do yourself-- I don't know I suppose it depends on how keen you are to follow it up or you know even the adults, depends on how long they've had it for if it's just a one off I don't know. I say that every person with asthma has eczema. There's obviously a correlation they're always in and

*out of the doctor's to something looks like a breakdown in your immune system somewhere. **Participant 55***

*It'd be nice if they could give you more info. Yes, well lots of my doctors say, "Well okay." I mean, he does give me options and creams but that is all it is. There's never any, you know "Oh maybe try this or try that." Like I would've never thought about clinical trials or anything like that. Yes, that would be interesting to know if they can bring that other, "Okay, we've used cortisone cream for forty years, maybe we'll try something else." That would be a good conversation to have. **Participant 64***

*Maybe give a lot more options because I know for me, I've only been given one option at a time. Unless I do go to different doctors in different areas, sort of thing. The ones that I've been to in SUBURB, they've given me one and when I came to the LOCATION, they have me a different steroid cream. And I was living in LOCATION for a while. They didn't prescribe me anything. They only just gave me an option to go to a pharmacist and get this one type of cream. There wasn't anything else. So, maybe in the future, there could be a long list or different types of options to choose from or depending on how severe it is or isn't. **Participant 75***

Table 9.4: Expectations of health professional communication

| Expectations of health professional communication | 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 expects health professionals to be compassionate/empathy/take eczema seriously | 28 | 28.00 | 5 | 45.45 | 4 | 15.38 | 12 | 29.27 | 7 | 31.82 |
| Participant expects more accurate information about eczema/education about eczema for health professionals so they are better equipped to explain eczema. | 20 | 20.00 | 3 | 27.27 | 8 | 30.77 | 5 | 12.20 | 4 | 18.18 |
| Participant expects health professionals to listen to the patient, as they know their body best/more time | 14 | 14.00 | 0 | 0.00 | 6 | 23.08 | 3 | 7.32 | 5 | 22.73 |
| Participant expects to have a care plan or some type of follow-up (Including communication between health professionals) | 12 | 12.00 | 1 | 9.09 | 3 | 11.54 | 5 | 12.20 | 3 | 13.64 |
| Participant expects health professionals to provide information about all treatment alternatives, including both medical and complementary treatments | 10 | 10.00 | 1 | 9.09 | 0 | 0.00 | 7 | 17.07 | 2 | 9.09 |

| Expectations of health professional communication | Anxiety/Depression (n=39) | | Regional/Rural (n=41) | | Metropolitan (n=59) | | University educated (n=58) | | High school/Trade educated (n=42) | |
|---|---------------------------|-------|-----------------------|-------|---------------------|-------|----------------------------|-------|-----------------------------------|-------|
| Participant expects health professionals to be compassionate/empathy/take eczema seriously | 12 | 30.77 | 10 | 24.39 | 18 | 30.51 | 13 | 22.41 | 15 | 35.71 |
| Participant expects more accurate information about eczema/education about eczema for health professionals so they are better equipped to explain eczema. | 8 | 20.51 | 9 | 21.95 | 11 | 18.64 | 11 | 18.97 | 9 | 21.43 |
| Participant expects health professionals to listen to the patient, as they know their body best/more time | 6 | 15.38 | 8 | 19.51 | 6 | 10.17 | 8 | 13.79 | 6 | 14.29 |
| Participant expects to have a care plan or some type of follow-up (Including communication between health professionals) | 5 | 12.82 | 4 | 9.76 | 8 | 13.56 | 8 | 13.79 | 4 | 9.52 |
| Participant expects health professionals to provide information about all treatment alternatives, including both medical and complementary treatments | 4 | 10.26 | 4 | 9.76 | 6 | 10.17 | 5 | 8.62 | 5 | 11.90 |

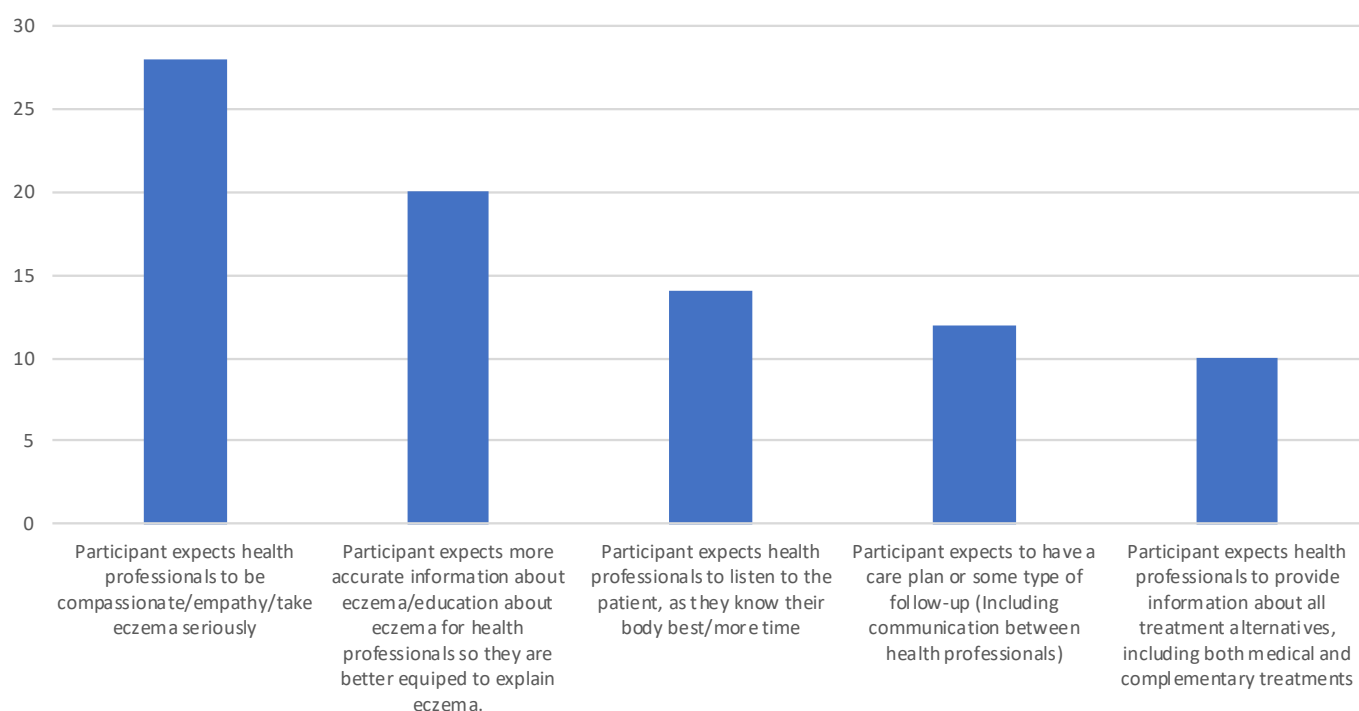


Figure 9.12: Expectations of health professional communication (% of all participants)

Expectation of care and support

Participants were asked whether there was anything they would like to see in relation to the care and support they receive. There were two main themes identified including recommendations to develop

opportunities to understand their condition, whether it is in relation to allergies, triggers or how to manage their condition (n=18, 18.00%). The second main theme was the recommendation for specialist services, either a clinic or telephone support line that is accessible to people diagnosed with AD (n=13, 13.00%).

Table 9.5: Expectations of care and support

| Expectations of care and support | 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 recommends more opportunities to understanding eczema (more information regarding allergies, triggers and how to manage eczema) | 18 | 18.00 | 2 | 18.18 | 5 | 19.23 | 4 | 9.76 | 7 | 31.82 |
| Participant recommends specialist clinics or services where they can talk to professionals (phone, online) | 13 | 13.00 | 1 | 9.09 | 2 | 7.69 | 8 | 19.51 | 2 | 9.09 |
| Participant recommends need of mental health/emotional support | 8 | 8.00 | 0 | 0.00 | 0 | 0.00 | 2 | 4.88 | 6 | 27.27 |
| Participant recommends being able to connect with other patients (support groups, online forums) | 7 | 7.00 | 0 | 0.00 | 4 | 15.38 | 3 | 7.32 | 0 | 0.00 |
| Participant recommends need for more information/awareness about available services | 7 | 7.00 | 0 | 0.00 | 3 | 11.54 | 2 | 4.88 | 2 | 9.09 |

| Expectations of care and support | Anxiety/Depression (n=39) | | Regional/Rural (n=41) | | Metropolitan (n=59) | | University educated (n=58) | | High school/ Trade educated (n=42) | |
|---|------------------------------|-------|--------------------------|-------|------------------------|-------|-------------------------------|-------|--|-------|
| Participant recommends more opportunities to understanding eczema (more information regarding allergies, triggers and how to manage eczema) | 6 | 15.38 | 9 | 21.95 | 9 | 15.25 | 8 | 13.79 | 10 | 23.81 |
| Participant recommends specialist clinics or services where they can talk to professionals (phone, online) | 4 | 10.26 | 6 | 14.63 | 7 | 11.86 | 9 | 15.52 | 4 | 9.52 |
| Participant recommends need of mental health/emotional support | 6 | 15.38 | 6 | 14.63 | 2 | 3.39 | 4 | 6.90 | 4 | 9.52 |
| Participant recommends being able to connect with other patients (support groups, online forums) | 1 | 2.56 | 3 | 7.32 | 4 | 6.78 | 5 | 8.62 | 2 | 4.76 |
| Participant recommends need for more information/awareness about available services | 3 | 7.69 | 1 | 2.44 | 6 | 10.17 | 3 | 5.17 | 4 | 9.52 |

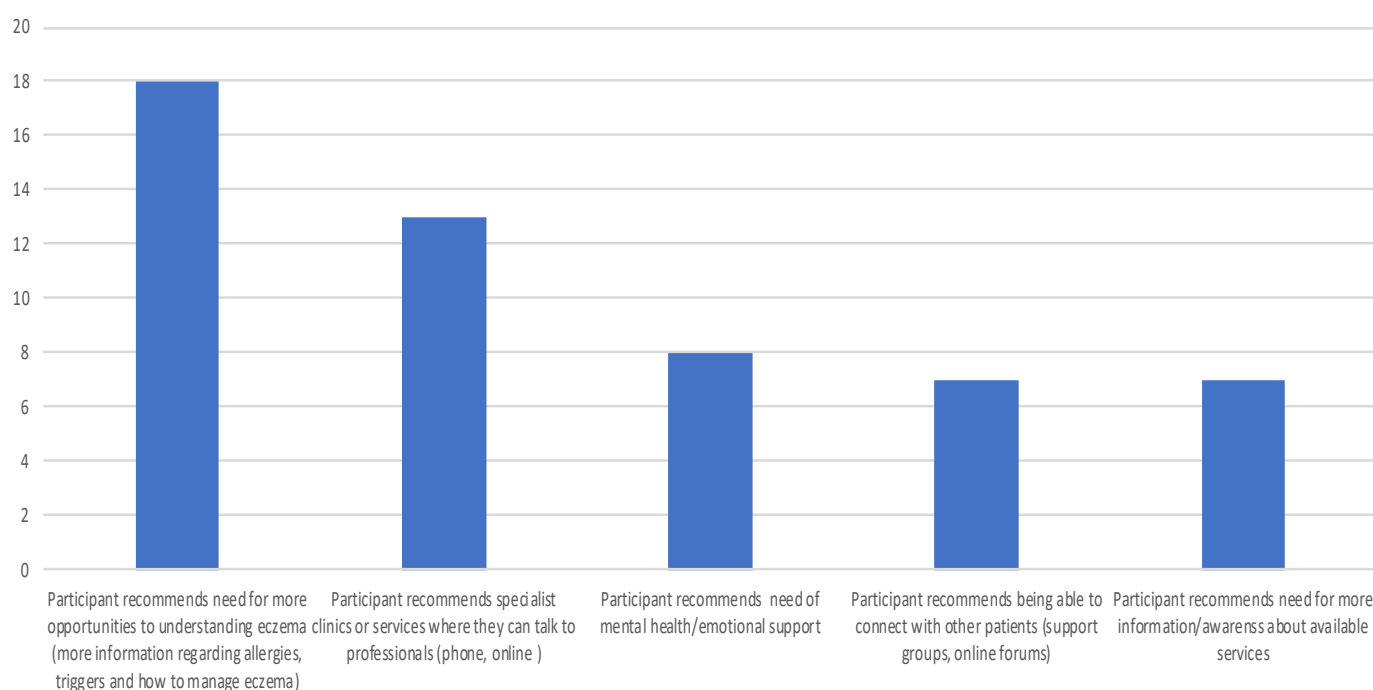


Figure 9.13: Expectations of care and support (% of all participants)

Messages to decision-makers about the treatment and care that people affected by AD

Participants were asked what their message to people who make decisions about their condition would be. There was one main theme noted by over half of the cohort (n=56, 56.00%) where participants had the message that their condition should be taken seriously and that there is a need for compassion and to actively listen to patients. This included that their condition can be debilitating and that it is life-long:

I definitely think that referrals to specialist being more easily obtained would be good. And there's a lot of things around my eczema of recent times ... And, look, I remember things as a child being very similar around my eczema, instead of being more really as a child, I was treated by the health system in those days. Which had sanitised nurses and support unavailable back then. Maybe my eczema might have been better across a number of years than what it has been. Yeah, so I think it's probably sort of a mixed bag of things that need to happen. And I think probably for a lot of people with eczema and stuff it probably starts, it's lifelong. It probably starts for most people in their childhood. It's not something you develop, often, out of the blue as an adult. It's something you probably grow up with, and live with, and by the time you get to be an adult, you're sort of almost like, "This is part of day to day life."

Participant 8

Yes, I think it would be that actually eczema is very debilitating and it's much more debilitating than they give it credit for. Even as a kid, you are ashamed of what you have, you are uncomfortable. You're always itching and it just doesn't look-- It's unsightly and you know that, you know within yourself that actually people are judging you for itching. It's actually much more debilitating than they would suggest it is. If I was talking to the Government, I would suggest that they pay more attention to their care system, so what care system they offer. I don't think dermatologists should be practicing in the area of eczema. They're other areas, they give more empathy into the business or it was for my dermatologist to seem to be his business. He didn't really care about it. He wasn't usually vested in knowing more. I think it would be better to have a support network that deals with eczema rather than dermatologists. **Participant 80**

That in almost every aspect of the life of someone with chronic eczema is affected negatively. We're unable to ... Okay, so I'm speaking from my point of view that it's harder to progress financially. There's a lot more mental and emotional strain on the person, so there

needs to be more support in these areas. I tried to get support when I went to a doctor a long time ago, one or two doctors, and neither of them were write a letter to say that I was unable to work, even though, it was almost impossible for me to work because I was just covered in eczema; I was covered in it, and it was emotionally really really difficult to work, and physically as well, it was painful, and I was bleeding over the clothes I was trying to sell, but there was no support because I wasn't using the medication that they said that I had to use, which would cause me more problems. I think there needs to be a bit more understand and a bit more support around that. Also that eczema is not just ... Eczema is a symptom of something. Eczema isn't the cause. It's not the issue, it's a result of something happening in the body, and it's not always going to be the same thing for everybody, so there needs to be more funding, I guess, in this research. I shouldn't say more, because I don't know how much funding there already is, but I would like to think that they would start to take into consideration the aspect of the issue being more than just a skin-related issue, and that it comes from somewhere.

Participant 91

There were 34 participants that whose message was to treat the condition holistically, including emotional support, having a care plan and being told about treatment options:

Just to take that holistic approach, that it's not just about fixing what you can see. Also, really and especially in our society now, eczema does have a big impact on your mental health and your relationships, and the worse that it is, the more of an impact it does have. Yes, so it's not just a thing that happens to your skin. It affects all of you and the people around you.

Participant 6

My message would be to look at them from a holistic perspective, so don't just give them access to a GP who just gives them steroids, and wet dressing treatments, but to give them a really well rounded service. So, for example, giving them a dietician, giving them the GP, the specialist, any other kind of ...all that they have. Yeah, so just looking at a whole person, giving them psychological help if they need that as well. Yeah.

Participant 34

I'd say that it's really important to take a look at statistics, and at its baseline, eczema is a condition, it's an autoimmune condition that is perpetuated by stress. I'd like, just as aside, I'd be curious to see the increase of the diagnosis of things like eczema, psoriasis, stress, and anxiety. I would love to see what the stats are now,

compared to fifty years ago. I think that would be a really interesting indicator. Then, of us needing to, again, take a holistic approach to, not so much combating, but supporting health, as a whole. It's things like, we need to be aware of the ridiculous workload that most people have. We need to be aware of the high incidence of stress and anxiety, and then, having an awareness of health and nutrition, and how that affects skin health, too. I guess, it's a bit of a tangent, but I'd say, what I would want to say is, we need to re-evaluate how our current health system can support well-being. I think we're missing the mark, particularly in mental health, and skin health. I guess, again, it comes back to that question you asked before, in terms of not booking our GP so that they have to see - work ten hour shifts, and miss those signs and signals, but just, supporting public health more, that's it. So that we have the resources that we need to live life. It's a dream, definitely. **Participant 46**

An additional 15 participants (15.00%) had the message that there needs to be more funding, not only for research but to develop health professionals to have more understanding and knowledge of the condition:

*I see. I would say that there needs to be easier access for acute situations that need advice urgently. Whether that's more...how do you get more doctors to become dermatologists, I don't know. I guess that or more funding for clinical nurse specialists that can take the dermatologist's advice, a common dermatologist's advice and implement that across a bigger population. Or a clinic you go to see, whether it's nurse practitioners or something that do dermatology. I would say the cost of creams and moisturizers and stuff on the PBS. It can get really expensive, whether or not you can get the wrong prescription because that hardens the, not cure, but treatment. **Participant 13***

*Yes. Definitely. I know that there is certain drugs and treatment available in the rest of the world, like in the US, that's unavailable here yet. I feel I don't think they're doing enough research or putting enough money towards these treatments or these drugs that could really help some people over here in Australia, who don't have the access to this treatments overseas. **Participant 38***

*I think....obviously putting money into research would be fantastic. I know that these things take a lot of time and a lot of money but it does affect so many people. Having a bit more dedication to it...I know there are a lot of people just get as a kid and get out of it. There's been so many more adults and older people with it that we're spending so much money and time on this throughout our lives and having a bit more money there for research and development would be fantastic. It's not just an itchy rash for a kid it can be somewhat debilitating disease throughout our lives like I can't be going, it's never going to go away. **Participant 72***

The final theme was a message to consider the cost of treatments and financial burden patients often face (n=11, 11.00%):

*Help us out with money. That would be nice. Making treats for us. Listen to us because I know there are some things out there, and I know that it's hard, you've got subsidies for pretty much a lot of things. My dad's got diabetes, so he gets subsidized, which frustrates me with that, but I think- (frustrating) It's just more so that, why does that get subsidized, and not this? I work right next to the Priceline Pharmacy, so when they've got 50% off stuff that I use, I will spend hundreds of dollars on it, because it's going to save me a lot of money. Anytime I have to pay full price on it I hate it, because I know I'm going to use it very quickly, and if I can get it on sale it will all add up for me. The biggest one is the financial side of things. It's a very expensive problem to have, or condition to have. I spent \$45 on creams alone, recently. That was on top of the sixty-something dollars I spent the day before on my medication. Within 24 hours, I spent over \$100, just on stuff to help me get through. **Participant 83***

*This actually cost them a lot of money. It's \$80 for a tube of cream that lasts two weeks. This is expensive. We should actually help fund some of this, because it's lifelong....just like they would consider a disease like diabetes. **Participant 85***

*Making it available financially, making it available in terms of getting the product. That's a long message, sorry...and my husband. He's had to take time off work to care for me quite a lot. **Participant 90***

Table 9.6: Messages to decision-makers

| Messages to decision-makers | 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's message is to be take eczema seriously: be compassionate, empathetic and try to understand that it can be debilitating and that it is life-long (listen to the patient) | 56 | 56.00 | 8 | 72.73 | 14 | 53.85 | 23 | 56.10 | 11 | 50.00 |
| Participant's message is treat eczema holistically, including supporting mental health, having care plans, choice of treatments and information in relation to all available options. | 34 | 34.00 | 2 | 18.18 | 8 | 30.77 | 16 | 39.02 | 8 | 36.36 |
| Participant's message is to invest in eczema including research, professional development of and access to eczema specialists and treatments | 15 | 15.00 | 2 | 18.18 | 4 | 15.38 | 7 | 17.07 | 2 | 9.09 |
| Participant's message is to provide understand the financial implications of eczema and provide financial support. | 11 | 11.00 | 0 | 0.00 | 3 | 11.54 | 2 | 4.88 | 6 | 27.27 |

| Messages to decision-makers | Anxiety/Depression (n=39) | | Regional/Rural (n=41) | | Metropolitan (n=59) | | University educated (n=58) | | High school/ Trade educated (n=42) | |
|---|---------------------------|-------|-----------------------|-------|---------------------|-------|----------------------------|-------|------------------------------------|-------|
| Participant's message is to be take eczema seriously: be compassionate, empathetic and try to understand that it can be debilitating and that it is life-long (listen to the patient) | 23 | 58.97 | 19 | 46.34 | 37 | 62.71 | 30 | 51.72 | 26 | 61.90 |
| Participant's message is treat eczema holistically, including supporting mental health, having care plans, choice of treatments and information in relation to all available options. | 11 | 28.21 | 15 | 36.59 | 19 | 32.20 | 19 | 32.76 | 15 | 35.71 |
| Participant's message is to invest in eczema including research, professional development of and access to eczema specialists and treatments | 4 | 10.26 | 9 | 21.95 | 6 | 10.17 | 10 | 17.24 | 5 | 11.90 |
| Participant's message is to provide understand the financial implications of eczema and provide financial support. | 5 | 12.82 | 5 | 12.20 | 6 | 10.17 | 5 | 8.62 | 6 | 14.29 |

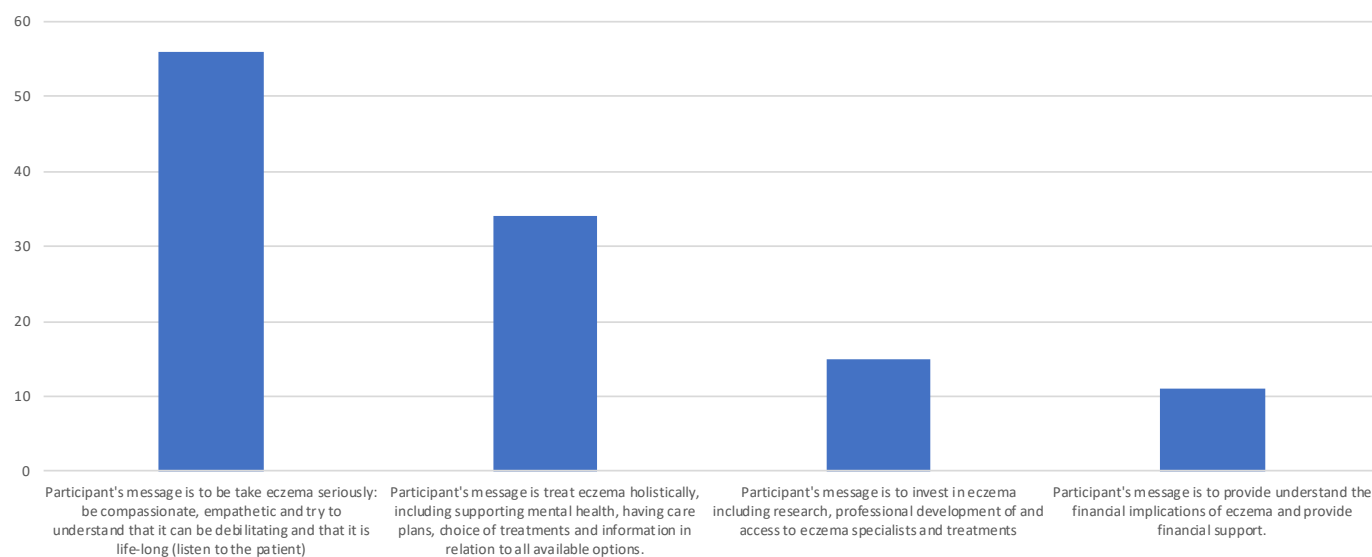


Figure 9.14: Messages to decision-makers (% of all participants)