"Not just a piece of skin in front of you" - a qualitative exploration of the experiences of adolescents with eczema and psoriasis with healthcare professionals.

Table S1: Illustrative data extracts from theme ECZ-1: **Address the emotional impact**

Not just a skin condition	"If people can see it and it's obviously going to make you very self-conscious, I think that again, that would be quite good to have, I don't know your doctor broach it possibly or just some information out there to say, you know, 'Hey if you do feel rubbish about it, it's OK but also, you know don't keep it inside.'…I think they should know that it does affect people not just physically but mentally and sort of, yeh it definitely does affect people in just more than one realm of their life; it's not just a skin condition. It's not like a cut that you can put a plaster over; it's something that needs to be addressed and, you know, looked after and stuff like that." *(4)*
	"I don't think there is any treatment that would completely eradicate it – so cream, creams and stuff like that are quite short term. So I think dealing with it emotionally can be more helpful than dealing with it physically because I think it's more damaging emotionally than physically." *(20)*
Try and understand how much it affects daily life	I'd like to say to all the doctors that I've had that you really, you just need to listen to your patient, because so many times I've felt like the doctor hasn't cared or has just told me, 'Oh, you'll grow out of it' or stuff like that and they don't, it's like they've not seen it as a real problem when it is, because they don't, it's like they don't understand how much it affects your life. Cos I know it's not like a big disease, but it can affect you loads. So just, just really listening and caring and finding out what works best and like actually trying to make it better rather than just being like, 'Oh, yeah, this cream's next', because that's just not helpful. That doesn't like make you feel better. It's not supportive."*(11)*
	"You don't wanna underestimate how much effort the patient is putting in to trying to maintain it and trying to make it better. And how much it's affecting like-, it's not the most debilitating disease but it's something that affects your whole daily routine and affects a lot of the decisions that you have to make as a patient. From like, from the moment you wake up to when you go to bed it's affecting your day. So just try and like talk to them about it and see like, help them to try and manage it." *(23)*
Filled in questionnaire, but results not discussed	"You, you will be given like a sheet on how it's affected your life and how it's made you feel. But it's not, it's never proceeded further than that sheet. I'm never asked about it or asked if I want, how I feel or if I think I would benefit from counselling or something like that. It's more focused on physical, physical aspects of it rather than the emotional and mental." *(9)*
Ask patient how they feel	"And I don't really think that they think about how you feel about having eczema. I mean, I know they're not like psychologists or anything, but they're your doctor. They should make you feel better, emotionally as well as like physically. So I think if someone keeps going back for eczema they should ask you how it affects your life, because people might not be so willing to volunteer that information… Especially when you go see a doctor, because you feel a bit nervous sometimes. Like there's so many times I've been to the doctor, I've been like 'right, I need to say this to them'. But it's just gone so quickly that I've like left with my prescription and I'm just like, 'I should have said something', but they don't, they don't, they see you as a patient sometimes and not just as a person." *(11)*
Be aware of embarrassment and anxiety that might surround eczema affecting intimate areas	"I mean, as an adult, there are intimate situations you don't, you feel uncomfortable. But, so my eczema's all over my body… They've never wanted to look at it unless I've insisted on them looking at it. So when it first spread to my breasts, I actually didn't know what it was because it was, it looked, well it looked like eczema but it looked a lot worse, especially because I didn't expect it to go there. So only once I've insisted that they look at it… I guess like spreading, so like if it would spread further, intimate areas, stuff like that. How would I deal with that...well you wouldn't really want to say, especially not to your, I would say especially not to your doctor just because I'd be uncomfortable." *(24)*

Be aware of associated guilt	“I've had that attitude from doctors where I should just be moisturising. I feel like, ‘Well I have been moisturising, that’s as much as I can do and that’s what I am doing.’ But still, I sort of get the problem, the feeling that, you know I'm not doing enough and that it's something that I'm doing and it's just… yeh it's just like what can I do? And then obviously cos it's your body you feel you have to take responsibility for it and but, you just can't help these things.” *(4)*
Doctor tried to help manage emotional impact of eczema scarring	“And so I went to the doctor I think when I was about 14 and the doctor sort of said, ‘OK well there's this thing called sort of coverage make-up that the Red Cross do and we could go and sort of get that sorted for you if you like?’ … I managed to get a prescription for the make-up and I sort of started using it and I just felt that… 'Ah I finally can sort of be me again.'” *(4)*

Table S2: Illustrative data extracts from theme PSO-1: **Address the emotional impact**

Want their Doctors to informally ‘check-in’ on well-being	“Keeping checks on someone’s mental health. Ask them, “’How’s this making you feel?’ or something like that. ‘How are you coping? How are you keeping up?’ And not like, ‘How are you, how are you responding to the medicine?’ ‘Oh, bad’ or, ‘Oh, good’ or something like that. ‘Oh great, off you go. And here’s another prescription.’” *(27)*
	“A young person, you know, like the psychological effects will be something that they might not even be aware is happening, but it's massively affecting like how they live their life and they're, you know, kind of like becoming more of a recluse…I'd definitely have like doctors kind of like look out for that and be aware of it and recommend that they speak to people and just ask them how they feel.” *(34)*
	“I know they could help me with it but they haven’t checked to see. I don’t know whether that’s because I- I can come across like everything’s okay maybe. I don’t know but they haven’t checked.”*(39)*
Would like Doctors to be more understanding of emotional impact. Feeling that Doctors don’t understand emotional effects and focus on medical side	“Just for them to be a little bit more understanding because we are young; we do - , we are conscious about what we look like, and that we are, we are growing up so we are still trying to discover who we are and what we are, especially with like friendships and relationships, and going off to uni and doing that sort of different things… I don’t think they realise as much how it can affect us.” *(31)*
	“I don’t think they understand as well as they could. I think they get the painful side but I don’t think they understand the like the negative impact it has on your social life and generally how you think and your outlook on life.” *(25)*
	“I mean, as long as you make a seriously big point about it, if you explain to them absolutely everything that’s happening they do tend, tend to take it a lot more seriously… But [uh] but it’s only if you really try to make sure that they notice it.” *(32)*
	“They were definitely focused on the more medical side. Which is obviously their speciality, but I think if they could have [pause 3 secs] reassured me about what to sort of- how to reduce the impact of it on my life, I think that would have been the biggest thing.” *(37)*
	“It was always a quick check up, look at it for five minutes and then just walk out, really. Try this, come back and see us. And that’s all it was, really. They never really got to talk to me about how I was feeling or psychological effects of it, just, quick look and see.” *(30)*
Offer psychological support	“But if actually they hate their life because they’ve got shitty skin, then maybe you need to ask the person if they need to see someone to talk about that. Or maybe you need to allot more time or see them a bit more frequently and stuff. They might not need another prescription but you might just want to check in with them or something like that.” *(27)*

PASI score completed but not looked at	“They do the PASI score of how it-, often basically your psoriasis like severity index which is that, that kind of thing about how much of your body is covered, kind of tends to correlate with this survey they do on how it's effecting your life… But I mean they only talk about it as much as, “Oh OK that's, it's bad,” or, “Oh, that's good.” I, they, they don't, I, I recall people being like, you know, “What should we do about that, because the score is very high?” It's more that just sort of for their records I feel-… they don't seem to massively be acting upon it.” *(34)*
GP gave support	“I found my GPs that I had whilst I was at university were just incredible about everything. They always made time for the emotional side effects of anything that you were going through.” *(27)*
Found it hard to find psychological support	“When I was first diagnosed at like 11, I found it quite hard to find support, you know, in the community or at the doctors or at the hospital. There was nothing really there in terms of support.” *(29)*
Found online resources helpful	“I haven’t had any one to one support, but I have, just reading and reading other experiences, just sort of indirectly supports me, if that makes sense.” *(30)*
Suggests having an option for emotional support while waiting for an appointment	“I understand how busy dermatologists are and the health care system is. And so I’m not sort of angry at the wait. But, I think, by having organisations, websites like this, charities, support organisations, talking about maybe the emotional aspects of it. Talking about alternative therapies, even. Might help patients waiting for their appointment or might even stop patients wanting a new appointment if they can deal with it in a different way like that.” *(29)*
Participant did NOT want to talk about psychological impact	*Interviewer: Would you have wanted to talk about the psoriasis stuff more?* “[Um] [pause 8 secs] no, I think talking about it always made it seem more real and I always quite liked to block it out.” *(25)*

Table S3: Illustrative data extracts from theme ECZ-2: **Give more information**

Eczema not properly explained	“Just make them more aware of like what eczema is and like why they're giving them certain creams and why they think that might help them, because I felt like, you know, ‘Here's a cream’; you know, it's more kind of like giving a solution like but not telling you about what you have.” *(15)*
Lack of information leading to confusion	“I honestly had some strange piece of advice, I was told not to eat egg for a while even though I had no, I actually, ho-honestly this is going to sound so stupid, when I was quite young I actually thought that egg was the initial part of eczema, like that’s how I pronounced it and I thought ‘ahh this makes total sense I’m just having too much egg’, like it’s a shame cos I really enjoyed like, you know, a nice poached egg or or fried egg in, on a, on a Saturday morning. You know and stuff, and I was like ‘oh okay, I think I've figured this out’ and I, I didn’t have egg for a while and it didn’t make a single difference.” *(18)*
Not explained as a child, and still do not understand as an adult	“But also that understanding that a child has, so really when you get to an adult they should, or a teen, because teens do have comprehension. But like, they should be telling you exactly what your condition is, as if it was from new to start off with. Because the understandings different now and you can fully comprehend what it is, and they should be telling you that. But they just believe that as a child you understood and you’ve carried on. When obviously you understand that your skin’s changing, you need to apply your creams because it’s your routine. But you don’t understand like what the creams are and what they’re doing.” *(10)*
Consultation directed to adult – child doesn’t understand why they have to apply creams	“Even when kids are little, always make sure you’re not, don’t talk directly to the parent because there were times I was sat there thinking ‘I don’t know what’s going on, these two people are having a conversation and I’m not being told’ and then I’d leave and mum would just be like, ‘Yeah, we have to put this on you,’ and I was, ‘Why? What is it? What’s in it?’ like tell them what it is and make sure they know what the condition is, what creams they’re being given, what treatments they’re being given. Ask if they have any questions cos I never got asked if I had

	questions." *(14)*
Language barrier preventing proper use of creams	"It was when it first hit because my mum didn't know how to look after it. I mean she'd been given all these steroid creams; she wouldn't know how to put them on me. She herself, being a native to Bangladesh, you know, understand half the time what the doctor was saying, so I'd have to try and memorise what the doctor was saying, and half the time I couldn't cos I was in agony, I couldn't bother listening. I just wanted to go home, lie down and have like a cold bath or something. So, we'd have like a rack of all these medications that did nothing." *(17)*
Lack of information because of lack of knowledge from GPs?	"I don't think anyone was ever unsympathetic. But I think it's just a lack of information within like, like right now I'd say I know more about vulvar eczema than like majority of GPs, which is like, I don't know, the fact that like, I- a Google article can tell me and like they don't know anything about it."*(16)*
Rushed appointments making it feel difficult to ask questions	"The problem I've found is that when I go in I have quite a long list of questions to ask so I say, 'Oh I'm gonna talk about this, I'm gonna talk about that', and then when I go in, because it's just all quite hurried I either forget all the things I wanted to ask, or I'm just like, 'OK'. They say, 'Do you have any more questions?' and I say, 'No, I don't', but I actually do but because their clock is ticking they don't want me to sit around and wait until the question comes back to me." *(22)*
Would like access to resources to provide more information	"Like a helpline to go and talk about, there's probably things out there but I haven't actually come along with, come across one that seems to have any sort of advice or information. I think people who have eczema have a lot of questions and I think people who have had eczema for a long time have even more questions about the condition. And so, I think that would be really handy to have … like a helpline or a charity or some organisation who's just sort of solely involved in eczema." *(4)*
Having it explained helped	*Interviewer: when you saw that nurse at your university? Was it your health centre or was it part of your…?* "Yeah, it's the medical centre which is part of the university. And I went to see her. I wasn't really hopeful because nothing works. I've seen two dermatologists now and none of that's worked. And she gave me, she actually explained to me, it's the first time anyone's ever explained why I have eczema like what causes eczema and the best ways to treat it… It took 19 years, but someone finally explained. I think doctors just want to give you a cream and move onto the next person." *(11)*
Dermatology nurses giving more detailed information than Doctors	*Interviewer: What sort of things have nurses spoken to you about that GPs and dermatologists have skimmed over?* "Some of it's just like technique… like ways to sort of apply creams and things like that that you don't really, you're like 'well you put it on, how difficult can it be?' 'Arr no, well if you do it like this and this and this, then it's actually sort of better' – things like that, that they don't, like dermatologists don't really have the time; well they probably wouldn't think to sort of do or how like what's the best order to do stuff in." *(12)*
	"Well I prefer, I know it might sound weird but I prefer to see the dermatologist nurse over the doctor because I think the nurse helps me more because they're more detailed than the doctor." *(1)*
Explained things well, able to ask questions	So they're quite friendly and we'll like have a nice chat. Yeah, they always explain everything quite well, and sort of ask you if there are any concerns or anything. *(12)*

Table S4: Illustrative data extracts from theme PSO-2: **Give more information**

'Psoriasis' never explained	"I think they just vaguely said that it's a skin disorder. Areas that could be affected, and I think that's all the information that they were given, really." *(30)*

	"Fully inform them of what it is because I don't think I got a clear picture of what psoriasis is." *(39)*
Did not realise psoriasis was a long-term condition	*Interviewer: So had doctors sort of explained that it was something that tends to stay with people for life or …* "Well, it wasn't the doctors that actually mentioned that, … it was actually my mother because she used to work in a medical centre herself in the 90s, so she did have a bit of experience…she was the one who told about, yes psoriasis was chronic. It isn't short term... if my mum hadn't worked at a health centre then I probably would have had my head in the sand." *(32)*
Risks of treatment not explained in person, just written in letter	"The phototherapy did scare me cos of the skin cancer risk that there is. But I wasn't taking too many sessions, so I did know that I was in the safe zone really." *Interviewer: Is that a concern that you had the opportunity to talk to the doctor's about?* "No. They just mentioned it in a letter that it was a risk and that's it." *(30)*
No explanation of potential side-effects	"The doctor said, 'We don't want you to be on these steroids for more than four to six weeks.' I don't know why." *(39)*
Give clear information re when to book next appointment	"I'm also the kind of person that I don't necessarily feel not comfortable doing it but I wouldn't book a doctor's appointment then like a week later. You know, unless I was asked to come back. So even though, even when sometimes I had a cream that didn't work, I still ended up waiting six months or whatever before coming back whereas it's best to just attack it straight on." *(38)*
Participant felt able to ask questions	"Oh the nurses and doctors were lovely… they were just really friendly nice to talk to, if you had any questions, it was, was comfortable." *(25)*

Table S5: Illustrative data extracts from combined sub-theme ECZ-3/PSO-3: **Appreciate patient research**

Respect the value of patient research	I would just also say don't have this sort of attitude that you know best because it's not a bad thing for a patient to have done their own research. And with something like psoriasis there is a chance that people will have, you know, really read up and looked online at stuff. And that's not necessarily a negative thing… but doctors always tend to view looking at things online like it's a negative thing." *(34, psoriasis)*
Found healthcare workers dismissive	"It was just like a natural like body scrub but it meant I could almost itch without causing any damage. So, and you could use it on a daily basis. So that was quite a good one and it, like I say, cos it's all natural and it has things in to help calm the skin down. It did, I found it helped. And I, when I told the dermatology nurse this, she just rolled her eyes at me."*(41, psoriasis)*
	"I think you kind of feel silly as well going to your doctor and saying, 'Well I read this on that.' I think doctors sort of, they look quite down on you that you've done your own research in a sense, cos they think you're being sort of a hypochondriac in a way you know, you're sort of kind of like, 'Well hang on, you know I do know better than you; I am… I did a degree, I'm a doctor after all and you're kind of just somebody who thinks they're a doctor because they looked up a couple of symptoms on WebMD,' but, you know I kind of feel like there should be a bit more of a better relationship I guess with the whole what is approved and what is not approved and what is good and what isn't good." *(4, eczema)*
Participant found really useful information online	"The doctors didn't mention to me about fragranced shampoos and shower gels so that is the first thing I took from online and that did stop my skin from being such, so irritated and angry and red and yeah, that's probably the main thing that I took from online." *(40, psoriasis)*
	Interviewer: the sort of biology of eczema, that's something that you came across through Googling rather than one of the medical practitioners?

	“Yeah…sort of Google it online and you get all these diagrams and stuff, and like how the skin works and things like that, which obviously in a 10 minute appointment they don’t have time to sort of explain the nitty gritty bits of it.” *(12, eczema)*
	“I’m pretty sure it was the Internet that first gave me the idea that I probably have eczema.” *(16, eczema)* *Note participant was referring to vulval eczema*

Table S6: Illustrative data extracts from theme ECZ-4: **“It’s not taken seriously”**

Parent demanding condition to be taken seriously	**“**Then it was really bad and then my dad was like, ‘OK nobody's doing anything; I don’t know why the doctors aren't taking this seriously,’ so he took me to the doctor and he sort of said, ‘Look she really needs something a bit stronger than sort of the zero point zero zero one percent of hydrocortisone’." *(4)*
Feels like the condition is not taken seriously	“You just feel like you're not taken seriously. I don’t know, I've always felt like that just when it comes to this condition I've never been taken seriously. I don’t know what has to happen - do I have to peel my skin off like to the eighth layer, just be like muscle and bone and then just be like, ‘Look - I have eczema guys, help me’.” *(4)*
	“It kind of made me lose a bit of faith in some of my doctors because they weren’t, didn’t take me seriously as a patient…I just felt like I wasn’t taken seriously. Which obviously makes you lose a bit of faith and a bit of confidence in not only yourself, because you don’t feel as though your problem is serious enough, but also because it didn’t feel like they’d picked up on it properly.” *(9)*
It’s not ‘just a rash!’	“So, when you’re dealing with doctors who don’t really, who don’t think of it as an actual condition – they just think of it as like, ‘oh… you’re just thinking about your appearance.’ …You want someone to listen and be like, ‘Look it’s not an irritation. It’s not mild. My skin feels like it’s actually on fire and it hurts’. But people just are like, ‘Look it’s just like a rash.’ And it’s like, ‘No, if it was a rash, I would not be complaining.’”*(10)*
	“It would be nice if healthcare professionals would sort of discuss it a bit more, I mean in my, albeit limited experience of talking about eczema to doctors it’s kind of been just treated like it’s one of those things and the thing is I think unless you’ve sort of experienced eczema you don’t realise is how painful it can be and how irritating it can be like not, not just the symptoms themselves but sort of the side effects from the symptoms but where you get lack of sleep and everything like that, that can be a lot worse than the eczema itself.” *(5)*
Just told that they’ll grow out of it	“Doctors don’t take it seriously. Like when I was in school they’d be like, ‘Oh, you’ll grow out of it’ and like they would try and manage it with loads of different creams. But obviously now, when I’ve still got it… I feel like some people think it’s not a big deal when they don’t know because they don’t have it. I mean, I know it’s not like a really serious illness, but it can feel like it when it gets bad.” *(11)*
Unpredictability of the condition - clears up on day of appointment	“You sort of book an appointment and then it miraculously it clears up the day that you go to the doctor and they're kind of like, ‘Well really I can't see anything; maybe you should just sort of stick with the really meek steroid and some moisturiser’.” *(4)*
	“I think the three months that it took me to get an appointment my skin had been fine and the guy took look, one look at me and was like, well why are you in here? … And, you know, like in two week’s time I might really have a stressful time and, and it, it would go from a high to a complete low.” *(13)*
Are emergency	“I have, in previous times, made emergency appointments where doctors have turned me away

appointments appropriate?	citing that this is not considered a emergency situation, so you have to just go back home, make an appointment as everyone else, and it has frustrated me, stressed me out; in turn led to depression that causes more…well more flared up eczema." *(17)*
Some do take it seriously; others do not	"My GP's very good because I've obviously I've been with him for, since we moved here, so seventeen years. But when I moved to uni I went to [city] to the GPs; they were not interested, so I found it easier to actually move back to my original GP." *(21)*

Table S7: Illustrative data extracts from theme PSO-4: **Feeling dehumanised / treat like a person**

Feeling dehumanised in Consultations	"You've got like a person who's not just a piece of skin in front of you." *(27)*
	"I felt a bit more like an interesting skin condition, than [Name] [surname]. I felt like this sort of-, this dehumanised sort of piece of skin that had come in … Coming into contact with someone who's got a skin condition, whether they're a GP or whether they're a friend, whether they're a stranger - try to think that this person isn't just a rash or a boil or a whatever. They are a person who happens to have this quite inconvenient problem with their skin. And they'd much rather you treated them as a- as the person they are than just a skin condition." *(37)*
Want their Doctor to take an interest in who they are	"I think it's important to take an interest in the person. And I understand how busy doctors are. But it's so helpful. It's so so helpful. And it puts the patient at ease. Just asking them about them, like 'What's your job?' or 'What are you studying?' and 'What are your interests?' It doesn't take long. But it makes them feel that you care." *(29)*
Positive experiences of feeling valued; felt that Doctor or nurse cared about their life	"This nurse, without looking went, 'Hi [Name], how are you?' And I was like [shocked face], how? Like how? And she just remembered me because we'd built up that rapport…But I think if you're made to feel a bit like, almost like special – you kinda feel a bit less bad about it." *(28)*
	"I know I told her when I first went in there that I used to swim and etcetera and she said, "My goal is to get you back swimming again," and at the moment I'm already swimming again so she was very happy with stuff like that. And she remembered that cos I went back couple of weeks ago and I told her that I was swimming and she was over the moon that I was swimming again and obviously that made me happy." *(40)*
	"So I've been in and certain dermatologists, the first time I met with him asked, y'know, what I was doing, what I was studying, what my hobbies were. And I was interested in the theatre and he was really interested in the theatre. So we talked a bit about that before we talked about anything medical, which is nice, cos it put me at ease. It really put me at ease. And I think that's such a lovely trait for a doctor to have and I understand how busy doctors are. And it must be difficult to take the time to do that. But it makes such a difference to the patient. Like it made such a difference to me. And I was so put at ease."*(29)*
	Interviewer: And if you had any questions for them would you feel OK about asking them things? "Yeah, I felt really confident in front of them, because they kind of like understood obviously, and they supported me quite a lot. And like I would talk to them about things that weren't even to do with my psoriasis; like I could talk to them about my school, and like everything, and just like say whatever I wanted, because they'd like understand and ask me stuff, so that it took my mind off of why I was at the hospital." *(26)*
Contrasting experiences of feeling 'shut-off' vs. properly listened to	"One of them was very, very business-like about it… 'Cos I went, I went in there thinking I need to explain every detail, everything about the timeline and be very, very precise about it all and the doctor was more or less "Yeh it's psoriasis" and I'd say a few more details, "No it's psoriasis." She was very, very business-like. And I sort of came out think oh that's quicker, quicker than I expected. I just felt they were quite shut-off about it whereas the next time I went round the the

	doctor, they were both female but they were both so, so different, the second was much more kind of sat down, listened, engaged like listened to everything I had to say first and then kind of made a diagnosis whereas the first lady kind of cut me off when she knew what it was…. I'm not saying I came out the first one crying or anything but I did think oh that's sounded business-like for a doctor." *(24)*

Table S8: Illustrative data extracts from theme ECZ-5: **Offer choice in treatment**

Lack of choice in treatments	"I haven't had much of a choice in the care that I've received, it's a sort of try this one and sort of like it or lump it, come back if it doesn't work and we will do something else, there's never been a list of a pros and cons presented for everything and let me choose my own care." *(5)*
Did not realise there were other cream options	"I was stuck on Doublebase, which is disgusting. It is, like. And it makes your skin feel greasy and I mean, like, sadly there is a thing about appearance in our culture. So when you have greasy skin because of your creams, you have that, well, people, and you smell like cream as well, never going to get over that. But it makes it hard. So you just think that you have to put up with it, whichever moisturiser they give you, and then eventually I was like, 'I really hate this cream. Can I have another?' And they went, 'Yeah, of course.' It was like, 'Oh, well you didn't say that originally'". *(10)*
	"I've been told before like, 'There's no other options for you. These are the only creams that are available.' And then you realise that there are and that the GP just didn't tell you about them. And that's really upsetting for, for the patient." *(23)*
'Accusational' about whether or not patients have been using the treatment	"As I got in my teens it sort of got a bit, I suppose a bit accusational in the sense that they weren't willing to give me things to help, cos they were like, 'Oh, how can we be sure you're actually doing it cos there's been no improvements, so you're not, you're not doing it,' 'Well, yes I am,' yeah." *(14)*
Not allowed allergy testing; 'half-hearted' explanation	"Straight up went to my doctor said 'Oh I'd like to be tested for what I'm allergic to' and 'Nah sorry we can't really do that we don't really have the facilities or I don't think this would affect your eczema in any particular way' or you know, these, these kind of like half-hearted jargon filled answers which you're kind of expected to just kind of be confused and mildly acceptant of. So I got a lot of that and then it was yeah it w-, it was kind of a situation where just deal with it yourself." *(18)*
One participant felt like they were given very limited treatments:	"It was really, really bad when I was a child… Yeh and the doctors didn't really do very much about it. In fact I was thinking about this the other day, they'd never really given me anything for it. I remember being recommended this stuff from [shop name] which was like this hemp cream and there was one that smelt kind of like that and there was another one which smelt like earth, it just smelt like soil that they gave me and I think that was the only thing they'd ever given me to deal with it." *(2)*
Find it difficult to question a Doctor's authority	"When I go to the doctors I feel like they're the person in charge so I can't really sort of be like, you know, 'I know that this suits me best,' if that makes sense. But I have sort of, I think when I was younger it was a big problem because they'd be like, 'Yeh do this, do this, do that'". *(4)*
Doctors giving good options	"A lot of the time they say, 'Oh I noticed that you've used this before, would you like something that's like the same brand but a different type?' So, like I've been using a cream and they said, "Do you want to use it as like a bath oil or something like that?" They are quite good with that, yeah, which is good." *(6)*
GP respects patient's expertise	"But then with my GP and that, he's, in the sense of, well if I go to him with anything, where he has known me so long with my eczema and I've seen him on like pretty much a weekly basis, they know that, I just go in there, I know what I need so I ask for it and then they give it to me and off I

	go cos like I know my body and I know what I need by now, so yeah." *(14)*

Table S9: Illustrative data extracts from theme PSO-5: **Think about how treatments will affect daily life**

Don't use the treatment because it takes too long/ can't continue with their normal activities	"I think while obviously they [Doctors] know exactly what they're talking about, it can be difficult to- to do exactly what they say, like I probably should be putting my creams on twice a day, every day, but I only put it on once a day because I literally don't have the time in the morning to put them on in the morning, and if I did put them on in the morning then my skin would not feel very nice – like it would feel greasy especially on the places that I put it, especially on my face. If I was going to try and put my cream on and then put my make-up on, like I would have greasy skin for the rest of the day and that's not something that I really want to deal with. So, I think doctors, while they do know what they're talking about, they should think about how the treatments are going to affect the patient's day-to-day life." *(36)*
Don't want to use treatments that smell bad	"Stuff like they gave me certain treatments for my hair like Cocois which is a smelly substance and I just said to them, 'Look, if I'm going to school in the morning I'm not gonna want my hair stinking of something,' and I just stopped using it off my own back cos I don't want to be at school and have people going, 'Oh, what's that smell?' and me having to explain. So I just stopped using that which probably if I did use it, it would have helped me but it's just one of those things that I don't think doctors realise that you have to be practical, the medicines have to help and they have to be practical with what you do in your everyday life." *(40)*
Don't want to use treatments that stain clothes	"Then there was this, there was this one that was like green and and I had psoriasis sort of under my arms and it was awful, because it would dye my school shirt. Ugh, I hated that." *(29)*
Useful way to deal with confusing treatment plans	"Yeah and that was really confusing. Like, because I couldn't use the cream that I had for my body on my face, because of it, I think it was steroid, or something, so I couldn't use it on my face. So, I had to like label my creams of like 'Body', 'Hair', 'Face'; and then I also had one that I needed to put in the bath, and I had one that I had to put on after the bath, and it was all really confusing. But we labelled them and kept them all together, so that we knew which one was which." *(26)*
Discuss the treatment options available	"So I just go and they'll say, 'Okay, use this for a month or until it goes away and then come and see us,' yeah. They've never said, 'Do you want to use this?' or 'Would you prefer to use this?'" *(30)*

Table S10: Illustrative data extracts from theme ECZ-6: **Lack of structure/conflicting advice**

Lack of structure	
Same things over and over again	"With eczema it's kind of like, 'Well we'll try this and if this doesn't get better, well come back and we'll try this, and if that doesn't get better then you'll come back and you'll try this and if that doesn't get' And it's just again and again and again and again and I kind of, it's just like you need some definitive, I think, structure to this condition." *(4)*
	"They're just prescribing me the same thing over and over again and seemingly expecting a different response." *(13)*
Would like a better picture of other options if treatments fail	"Know kind of like the line of treatments that are going to happen if that treatment doesn't work out. I think it's quite nice, for s- for a patient to know that like 'here's this, if this doesn't work, you're likely to have this and this and this' sort of thing." *(16)*
Only short-term flare-ups treated; no sense of	"So I usually visit the doctors when I have a flare-up or when my eczema get infected… But most of them have just been like, 'OK, take some, you know, here's a prescription, just use that for like three days and it should go away,' and generally it has in the short run obviously, but not in the

overall disease control	long.” *(15)*
Lack of structure exacerbated by moving GPs	“Maybe they should have like, if, when you go to a lot of different GPs, like more consistency between what is passed on between the practices, so that they know what’s been tried and what hasn’t. And so much of you going to the GP relies on what you remember and what you know working or not.”*(23)*
	“Especially as a young person you're often like flitting about, going to different houses, different areas, so keeping up with the same GP is difficult. And so they don’t really follow your story and it is like when you have a skin condition – it is like a story, it's not like, 'Here's some antibiotics, it will go in three days,' or, you know things like that. So you kind of need one professional or, you know a few sort of a regular, someone who knows what's happening.” *(3)*
	“My GP had literally been like all over the shop and my local GP at home, because I don’t live there, means it’s just whoever can see me, I don’t have one that I always see. But of course every time they pull out my records it’s just ‘eczema, eczema, eczema, eczema’… So that's why I think it took so long to be prescribed a strong cream because every single one was only seeing me for the first time or the second time – they weren’t appreciating it was something I’d been battling with for so long. ”*(8)*
Would like more structure in knowing when there should be a dermatology referral	“I feel like there should just be a bit more… just a set of steps I think where you know what to do, so that if you start at the bottom, and it's kind of like a flowchart if that makes sense… I also feel like if say you’ve been to the doctor like eight times for the same ailment and it hasn’t gotten better and you’ve kind of also asked if you could go and get referred to somebody who might just know a bit more without being horribly disrespectful to the doctor themselves.” *(4)*
	“I remember asking if I could go to a dermatologist and they were like, ‘No, you can’t go to a dermatologist unless you’ve tried every single option available and it doesn’t work.’ But sometimes you feel like you have.” *(23)*
Decision to refer to dermatology felt negative/ an inconvenience	“The doctor was… I could see in her face that she, at this point, was well exhausted of dealing with it, it seemed like it. Like she couldn’t be bothered to deal with my eczema, or deal with the medication; deal with my mum's questions and so forth. So, for her sake, you know what, ‘Go see this dermatologist,’ and from then on it was usually my dermatologist who kept an eye on things and rarely did I go see the doctors.” (P53
	“It was such a like a, a labouring question like ‘okay I’ll have to write a letter to some dermatologists and we will get them to see you if they’ve got capacity’ and stuff like that.” *(18)*
Dermatology referral felt straightforward	“’Well come back in like two weeks or something, and if it's still not fine and sort of refer you then,’ sort of type thing. But yeah I think it was, yeah my mum who was like just go and ask to be referred, which it was actually quite easy, I thought it would be more difficult than it was, but they were sort of like, ‘Yeah sure’.” *(12)*
Given a structured treatment ‘itinerary’ in dermatology	“Seeing the dermatologist, and I actually cried during my consultation because I was so upset about the way I looked and the way I felt. And, I remember she, she just sat me down and said, ‘We’re gonna to sort this out…We’re gonna get you back on the right track where you should be.’ And she reeled me off with like a massive itinerary of what would be happening for like the next year and a half.” *(9)*
Discharged from dermatology too soon	“What happened with me and what happens with my sister is that, once sort of the eczema has gotten a little bit better, they're like, ‘Oh hooray, hazar. you know, it's cleared,’ and it's like not really, this is just perhaps a better day than most. So, you get discharged and then you have to go through the whole process again.” *(4)*
Conflicting Advice	
Dermatologists and GPs disagreeing is	“A lot of the doctors have a lot of varying opinions on what to prescribe, what to do, what are, what methods may promote the best results. And that’s been an issue as well because I've been moving from many different doctors and they all have their own opinions on how something

frustrating	should work or shouldn't work. That's also been quite frustrating as well." *(17)*
Conflicting messages over steroid use	"And like you also get a huge amount of mixed messages. Like, as I said, I've used hydrocortisone and I've used it on my face and I've used it on my body. And I've been told by some doctors that like I can never use it on my face, like it's completely inappropriate. Like, as I said, the chemist refused to sell it to me. Other doctors have said, 'You can use it on your face. You can use it on your eyelids. You can use it for as long as you want.' Like it's very mixed messages. … So you don't know what you're doing really. And that's just like, that's quite frustrating. Because then you go to a new doctor and you're like, 'Oh, yes, I've been doing this and this has been working, blah, blah, blah.' And they're like, 'Oh, well, you can't do that. Like that's awful. You have to stop doing that immediately. But there's no other options.' And you're like, 'Oh, okay, well, what, what am I meant to do?'" *(23)*
Being told they're doing it 'wrong'	**"**He was telling me that I was wrong, that I needed to forget everything my doctors have ever told me and he prescribed me medicine I'd had before and a cream I told him that didn't work. He wasn't very nice." *(10)*