

Evaluating the appropriateness of existing health-related quality of life measures in lichen planus

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Supplementary Table 1. Cronbach's alpha if-item-deleted for the DLQI, ESS, Scalpdex and OLPSSM (Week 4)

PRO measure	Total score	Domain score		
		Scalpdex 'Symptoms'	Scalpdex 'Functioning'	Scalpdex 'Emotions'
DLQI (n=108)				
Item 1: 'Over the last week, how itchy, sore, painful or stinging has your skin been?'	0.920	-	-	-
Item 2: 'Over the last week, how embarrassed or self-conscious have you been because of your skin?'	0.909	-	-	-
Item 3: 'Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?'	0.908	-	-	-
Item 4: 'Over the last week, how much has your skin influenced the clothes you wear?'	0.909	-	-	-
Item 5: 'Over the last week, how much has your skin affected any social or leisure activities?'	0.903	-	-	-
Item 6: 'Over the last week, how much has your skin made it difficult for you to do any sport?'	0.907	-	-	-
Item 7: 'Over the last week, how much has your skin affected your work or study?'	0.918	-	-	-
Item 8: 'Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?'	0.913	-	-	-
Item 9: 'Over the last week, how much has your skin caused any sexual difficulties?'	0.913	-	-	-
Item 10: 'Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?'	0.921	-	-	-
ESS (n=108)				
Item 1: 'Sitting and reading'	0.829	-	-	-
Item 2: 'Watching TV'	0.831	-	-	-
Item 3: 'Sitting, inactive in a public place (e.g. a theatre or a meeting)'	0.845	-	-	-
Item 4: 'As a passenger in a car for an hour without a break'	0.845	-	-	-
Item 5: 'Lying down to rest in the afternoon when circumstances permit'	0.841	-	-	-
Item 6: 'Sitting and talking to someone'	0.864	-	-	-
Item 7: 'Sitting quietly after a lunch without alcohol'	0.823	-	-	-
Item 8: 'In a car, while stopped for a few minutes in the traffic'	0.853	-	-	-
Scalpdex (n=37)				

PRO measure	Total score	Domain score		
		Scalpdex 'Symptoms'	Scalpdex 'Functioning'	Scalpdex 'Emotions'
Item 1: 'My scalp hurts.'	-	0.345	-	-
Item 2: 'My scalp condition makes me feel depressed.'	-	-	-	0.935
Item 3: 'My scalp itches.'	-	0.501	-	-
Item 4: 'I am ashamed of my scalp condition.'	-	-	-	0.933
Item 5: 'I am embarrassed by my scalp condition.'	-	-	-	0.932
Item 6: 'I am frustrated by my scalp condition.'	-	-	-	0.933
Item 7: 'I am humiliated by my scalp condition.'	-	-	-	0.936
Item 8: 'My scalp condition bleeds.'	-	0.695	-	-
Item 9: 'I am annoyed by my scalp condition.'	-	-	-	0.934
Item 10: 'I am bothered by the appearance of my scalp condition.'	-	-	-	0.932
Item 11: 'My scalp condition makes me feel self-conscious.'	-	-	-	0.935
Item 12: 'I am bothered that my scalp condition is incurable.'	-	-	-	0.936
Item 13: 'My scalp condition affects how I wear my hair (hairstyle, hats).'	-	-	0.795	-
Item 14: 'I am bothered by people's questions about my scalp condition.'	-	-	-	0.940
Item 15: 'My scalp condition affects the color of clothes I wear.'	-	-	0.844	-
Item 16: 'I am bothered by the persistence/reoccurrence of my scalp condition.'	-	-	-	0.935
Item 17: 'I feel stressed about my scalp condition.'	-	-	-	0.934
Item 18: 'Caring for my scalp condition is inconvenient for me.'	-	-	0.783	-
Item 19: 'I feel that my knowledge for caring for my scalp is adequate.'	-	-	-	0.949
Item 20: 'The cost of caring for my scalp condition bothers me.'	-	-	-	0.949
Item 21: 'My scalp condition makes my daily life difficult.'	-	-	0.743	-
Item 22: 'My scalp condition makes me feel different from others.'	-	-	-	0.934
Item 23: 'My scalp condition makes it hard to go to the hairdresser/barber.'	-	-	0.756	-
OLPSSM (n=33)				
Item 1: 'When you brushed your teeth?'	0.881	-	-	-
Item 2: 'When you ate food?'	0.847	-	-	-
Item 3: 'When you drank liquids?'	0.852	-	-	-
Item 4: 'When you smiled?'	0.843	-	-	-

PRO measure	Total score	Domain score		
		Scalpdex 'Symptoms'	Scalpdex 'Functioning'	Scalpdex 'Emotions'
Item 5: 'When breathed through your mouth?'	0.871	-	-	-
Item 6: 'When you talked?'	0.850	-	-	-
Item 7: 'When it was touched?'	0.870	-	-	-

PRO Patient-reported outcome

DLQI Dermatology Life Quality Index

ESS Epworth Sleepiness Scale

OLPSSM Oral Lichen Planus Symptom Severity Measure

Supplementary Table 2: Quotes from qualitative interviews discussing concept relevance for the DLQI, ESS, Scalpdex and OLPSSM

PRO measure	Item	Supporting quotes
DLQI	Item 1: 'Over the last week, how itchy, sore, painful or stinging has your skin been?'	<ul style="list-style-type: none"> “...‘A lot’... There were some good days that would have been a lot where they would be some days it would be not much...” (Female participant aged 72 with moderate LPP, US) “Only gum has itching... I do that gargling with medicine... it's relief within two, three hours... it's pain, when I brush... I eat or something I'm drinking, it's a little pain...” (Female participant aged 73 with moderate MLP, US)
	Item 2: 'Over the last week, how embarrassed or self conscious have you been because of your skin?'	<ul style="list-style-type: none"> “...‘A little’ because I haven't done much this week... when people can see how red it is... because of the sparseness of the hair.” (Female participant aged 72 with moderate LPP, US) “...Stuff like that doesn't bother me... I can't get all upset over stuff I can't control.” (Female participant aged 64 with moderate LPP, US)
	Item 3: 'Over the last week, how much has your skin interfered with you going shopping or looking after your home or garden?'	<ul style="list-style-type: none"> “...Looking after my home or yard, that's, uh, not relevant. The going shopping, going out period, is very much.” (Female participant aged 44 with severe CLP, US) “...that isn't relevant to my lichen planus... I will look after like my patio, clean my patio, stuff like that.” (Female participant aged 41 with moderate MLP, US)
	Item 4: 'Over the last week, how much has your skin influenced the clothes you wear?'	<ul style="list-style-type: none"> “...‘A lot’... due to the, the genitalia area, it's more comfortable for me to wear, uh, like leggings versus jeans or anything like that.” (Female participant aged 45 with moderate MLP, US) “...not relevant because it's oral.” (Female participant aged 41 with moderate MLP, US)
	Item 5: 'Over the last week, how much	<ul style="list-style-type: none"> “...‘Very much’... I don't have a social life... because of LP, I have no life. I don't want to be seen. I

Supplementary Table 2: Quotes from qualitative interviews discussing concept relevance for the DLQI, ESS, Scalpdx and OLPSSM

PRO measure	Item	Supporting quotes
	has your skin affected any social or leisure activities?’	<p><i>look awful.</i>” (Female participant aged 44 with severe CLP, US)</p> <ul style="list-style-type: none"> • <i>“...It doesn’t prevent me from going out or socializing or anything like that... I don’t have any issues...”</i> (Female participant aged 45 with moderate MLP, US)
	Item 6: ‘Over the last week, how much has your skin made it difficult for you to do any sport?’	<ul style="list-style-type: none"> • <i>“... ‘A little’... I walk and that’s about it as a sport... I would have to put a hat on and it’s maybe too hot for my head to have a hat on. Therefore, it affects it.”</i> (Female participant aged 72 with moderate LPP, US) • <i>“... ‘Not at all’... there’s not a whole lot of sports that I do expect play croquet and it’s too gosh darn hot down here...”</i> (Female participant aged 75 with moderate LPP, US)
	Item 7: ‘Over the last week, has your skin prevented you from working or studying? If "No", over the last week how much has your skin been a problem at work or studying?’	<ul style="list-style-type: none"> • <i>“... ‘A little’... my, um, responsibilities at work, talking... is a huge part of my job...”</i> (Female participant aged 45 with moderate MLP, US) • <i>“... ‘Not at all’... the pain wasn’t so much that it made talking during work challenging.”</i> (Female participant aged 41 with moderate MLP, US)
	Item 8: ‘Over the last week, how much has your skin created problems with your partner or any of your close friends or relatives?’	<ul style="list-style-type: none"> • <i>“... ‘Very much’... being, um, intimate with my husband... That can’t happen right now...”</i> (Female participant aged 45 with moderate MLP, US) • <i>“... ‘Not at all’... they accept me whatever it is.”</i> (Female participant aged 72 with moderate LPP, US)
	Item 9: ‘Over the last week, how much has your skin caused any sexual difficulties?’	<ul style="list-style-type: none"> • <i>“...it just caused difficulties when we were kissing...”</i> Interviewer: <i>“...has it ever caused...sexual difficulties...?”</i> <i>“Yes, it has.”</i> (Female participant aged 41 with moderate MLP, US) • <i>“...Not relevant because I don’t have sex. I wouldn’t want a man to see my body.”</i> (Female participant aged 44 with severe CLP, US)
	Item 10: ‘Over the last week, how much of a problem has the treatment for your skin been, for example by making your home messy, or by taking up time?’	<ul style="list-style-type: none"> • <i>“... ‘A lot’... I had a lot of irritation at the beginning of the week. So I had to take the steroids a lot more frequently, try to remember to take them, um, stop what I was doing to take them...”</i> (Female participant aged 41 with moderate MLP, US) • <i>“... ‘Not at all’... the only treatment that I’ve done is the injections... it didn’t take much time at all... five minutes... it was very, uh, inconsequential and convenient.”</i> (Female participant aged 45 with moderate MLP, US)
ESS	Item 1: ‘Sitting and reading’	<ul style="list-style-type: none"> • <i>“...during the day, I would say ‘slight’ and ‘moderate’ if it was the evening...”</i> Interviewer: <i>“...is this question relevant to your experience of lichen planopilaris?”</i> <i>“...no... it’s more in general to what I</i>

Supplementary Table 2: Quotes from qualitative interviews discussing concept relevance for the DLQI, ESS, Scalpdex and OLPSSM

PRO measure	Item	Supporting quotes
		<p><i>do... in life, maybe in a particular day.</i>" (Female participant aged 61 with moderate LPP, US)</p> <ul style="list-style-type: none"> • <i>"...during the daytime, I would never fall asleep... before going to bed, just to kind of relax, that would then be the intention to some extent, but I wouldn't fall asleep right away then either... 0."</i> (Female participant aged 52 with moderate CLP, Germany)
	Item 2: 'Watching TV'	<ul style="list-style-type: none"> • <i>"...'moderate chance'..." Interviewer: "...is that relevant to your experience of mucosal lichen planus?"</i> "Yeah... I'll sit up when I'm watching TV and then I'll catch myself lying down... I'll just fall asleep." (Female participant aged 39 with severe MLP, US) • <i>"...0... I watch TV every single day... I only see things, which I'm very interested in, so I, I never sleep."</i> (Female participant aged 76 with severe CLP, US)
	Item 3: 'Sitting, inactive in a public place (e.g., a theatre or a meeting)'	<ul style="list-style-type: none"> • <i>"...at a theatre... 3. At a meeting, I wouldn't..." Interviewer: "...because of your mucosal lichen planus...?"</i> "Yes... I've gone to the theatre with my grandson and, and I fall asleep..." (Female participant aged 61 with moderate MLP, US) • <i>Interviewer: "...have you ever dozed in a public place due to your cutaneous lichen planus?"</i> "...The meeting, no... if I'm inactive outside in a park, then no... if I'm sitting in a, in a theatre like watching a play or something like that and it's not really grabbing my attention... 'slight chance'." (Female participant aged 45 with moderate CLP, US)
	Item 4: 'As a passenger in a car for an hour without a break'	<ul style="list-style-type: none"> • <i>"...depends on who's driving... 2... I have another illness that, uh, causes a great deal of fatigue... any fatigue that I do feel, I never, uh, attribute that to, to lichen planus."</i> (Female participant aged 45 with moderate CLP, US) • <i>"...'Never'... if I'm sitting there as a passenger in a car for five hours at night, then it's actually possible..."</i> (Female participant aged 60 with mild MLP, Germany)
	Item 5: 'Lying down to rest in the afternoon when circumstances permit'	<ul style="list-style-type: none"> • <i>"...1... maybe I had a rough sleep..." Interviewer: "...is that due to your symptoms?"</i> "Yes... because of, um, itching and some pain." (Female participant aged 61 with moderate LPP, US) • <i>"No, even if I had the option... I would need to be sick before I would lie down in the afternoons."</i> (Female participant aged 52 with moderate CLP, Germany)
	Item 6: 'Sitting and talking to someone'	<ul style="list-style-type: none"> • <i>"...if it's in the morning, no... at night... it's a high chance... on the telephone or like when I do go home and hang with my family... and it's like 3:00 in the morning, oh I'm going to doze because I'm tired."</i> (Female participant aged 44 with severe CLP, US)

Supplementary Table 2: Quotes from qualitative interviews discussing concept relevance for the DLQI, ESS, Scalpdex and OLPSSM

PRO measure	Item	Supporting quotes
		<ul style="list-style-type: none"> • “0... if I’m already sitting somewhere talking to someone then I’m 100% focused and I’m interested... Otherwise I would cancel the appointment and say, ‘I don’t feel like meeting you’.” (Female participant aged 41 with mild MLP, Germany)
	Item 7: ‘Sitting quietly after a lunch without alcohol’	<ul style="list-style-type: none"> • “...It depends if that lunch is out in public or if that lunch is at home. If I am home, I probably will, so number 2...” Interviewer: “...is this question relevant to your experience of lichen planus?” “Um, yeah.” (Female participant aged 399 with severe MLP, US) • “I’m much too active, I spend very little time sitting. No, I don’t doze... It never happens in my normal everyday life.” (Male participant aged 55 with moderate MLP, Germany)
	Item 8: ‘In a car, while stopped for a few minutes in the traffic’	<ul style="list-style-type: none"> • “It’s certainly possible... ‘slight chance’... I would be ‘gone’ for a moment, but just for a moment.” (Female participant aged 61 with moderate CLP, Germany) • “...‘would never doze’... if those feelings or thoughts begin to come in my head, I just don’t drive... I just avoid it.” (Male participant aged 41 with moderate MLP, US)
Scalpdex	Item 1: ‘My scalp hurts.’	<ul style="list-style-type: none"> • “...‘Sometimes’... the hurting pain that you experience... that sort of pain really is, so I can very relevant.” (Male participant aged 46 with severe LPP, US) • “...my scalp didn’t hurt...” Interviewer: “...your scalp has never hurt...?” “Right.” (Female participant aged 64 with moderate LPP, US)
	Item 2: ‘My scalp condition makes me feel depressed.’	<ul style="list-style-type: none"> • “I would say ‘Often’... because of the pain... itching... affects your emotional wellbeing, maybe social situations you might be kind of avoiding... or you feel kind of anxious... that would make you kind of be depressed.” (Male participant aged 46 with severe LPP, US) • Interviewer: “...for the condition...you’ve never felt sad or low?” “Right.” (Female participant aged 64 with moderate LPP, US)
	Item 3: ‘My scalp itches.’	<ul style="list-style-type: none"> • “...‘Often’... That’s one of the aspects of, uh, lichen planus... the itching... so very relevant actually...” (Male participant aged 46 with severe LPP, US) • “‘My scalp itches’... ‘Never’” (Female participant aged 55 with moderate LPP, Germany)
	Item 4: ‘I am ashamed of my scalp condition.’	<ul style="list-style-type: none"> • “...‘Sometimes’... feeling anxious or kind of avoiding social situations because of your condition...” (Female participant aged 46 with severe LPP, US) • “...I understand it’s something I can’t help. I’m not ashamed of it.” (Male participant aged 70 with severe LPP, US)

Supplementary Table 2: Quotes from qualitative interviews discussing concept relevance for the DLQI, ESS, Scalpdex and OLPSSM

PRO measure	Item	Supporting quotes
	Item 5: 'I am embarrassed by my scalp condition.'	<ul style="list-style-type: none"> • "... 'All the time' because I'm constantly trying to hide it... I don't like the way I feel about it and I don't want others to see it." (Female participant aged 55 with moderate LPP, US) • "I'm only embarrassed if somebody is really asking me and querying me about it. Other than that, never" (Female participant aged 75 with moderate LPP, US)
	Item 6: 'I am frustrated by my scalp condition.'	<ul style="list-style-type: none"> • "'Sometimes'... frustrated, upset that nothing worked, can be done, or it's not making progress... it's out of my control..." (Female participant aged 55 with moderate LPP, US) • "No, I've never been that." (Male participant aged 54 with mild LPP, Germany)
	Item 7: 'I am humiliated by my scalp condition.'	<ul style="list-style-type: none"> • "... 'Sometimes'... It's relevant." (Female participant aged 69 with moderate LPP, US) • "... 'Never'. I don't think I ever felt humiliated... humiliated is more if somebody made you... feel that way, um, instead of you feeling it without somebody necessarily even knowing or seeing." (Female participant aged 55 with moderate LPP, US)
	Item 8: 'My scalp condition bleeds.'	<ul style="list-style-type: none"> • "... 'Rarely'... only when I scratch it until the skin is torn... that's really rare." (Male participant aged 54 with mild LPP, Germany) • "... 'Never'. Not really get to that point. Just red." (Female participant aged 55 with moderate LPP, US)
	Item 9: 'I am annoyed by my scalp condition.'	<ul style="list-style-type: none"> • "... 'Sometimes'... As soon as it itches, I immediately think: 'Oh, it's coming back again now'..." (Male participant aged 52 with severe LPP, Germany) • "... 'Never'... It's always going to be there... What are you going to do, let it bother the rest of your life?" (Female participant aged 75 with moderate LPP, US)
	Item 10: 'I am bothered by the appearance of my scalp condition.'	<ul style="list-style-type: none"> • "... 'All the time'... I have to wear my hair pulled back... like a ponytail or a clip." (Female participant aged 69 with moderate LPP, US) • "No, because I can't see it." (Female participant aged 75 with moderate LPP, US)
	Item 11: 'My scalp condition makes me feel self-conscious.'	<ul style="list-style-type: none"> • "... 'All the time'... I'm constantly thinking about it... is my hair the right way? I'm just very aware of it." (Female participant aged 55 with moderate LPP, US) • "That's not the case either, 'Never'." (Male participant aged 54 with mild LPP, Germany)
	Item 12: 'I am bothered that my scalp condition is incurable.'	<ul style="list-style-type: none"> • "I'm bothered my scalp condition is incurable... Yeah. That does bother me, often, I think in those terms." (Male participant aged 70 with severe LPP, US) • "... I know that of course. So 'Never'... I never really thought... that it's curable." (Male participant

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PRO measure	Item	Supporting quotes
		aged 54 with mild LPP, Germany)
	Item 13: 'My scalp condition affects how I wear my hair (hairstyle, hats).'	<ul style="list-style-type: none"> • "... 'Always'... I wear my hair in such a way that this area is not visible... when my hair is wet or I haven't blow-dried it properly, it's visible then." (Male participant aged 52 with severe LPP, Germany) • "...not really, 'Never'." (Male participant aged 70 with severe LPP, US)
	Item 14: 'I am bothered by people's questions about my scalp condition.'	<ul style="list-style-type: none"> • "That is 'Rarely', because most people don't know." (Female participant aged 69 with moderate LPP, US) • "They've never asked me... if they would, I would be bothered, but they don't." (Female participant aged 55 with moderate LPP, US)
	Item 15: 'My scalp condition affects the color of clothes I wear.'	<ul style="list-style-type: none"> • "... 'Sometimes'... I wear a lot of black... If I'm having a flare..." (Female participant aged 44 with moderate LPP, US) • "'Never'... the colours that I wore before are my favourites and I'm going to continue to wear them..." (Female participant aged 75 with moderate LPP, US)
	Item 16: 'I am bothered by the persistence/ reoccurrence of my scalp condition.'	<ul style="list-style-type: none"> • "... 'Often'... it just keeps coming and going... no rhyme or reason. I can't figure it out. It just seems to always be there." (Female participant aged 55 with moderate LPP, US) • "... 'Never'." (Female participant aged 64 with moderate LPP, US)
	Item 17: 'I feel stressed about my scalp condition.'	<ul style="list-style-type: none"> • "'Sometimes'... I'm concerned whether it will improve, or am I going to have to deal with this the rest of my life or is it going to get worse and wind up with no hair?" (Female participant aged 72 with moderate LPP, US) • Interviewer: "You've never been stressed by that then..." "No." (Female participant aged 64 with moderate LPP, US)
	Item 18: 'Caring for my scalp condition is inconvenient for me.'	<ul style="list-style-type: none"> • "'Often'... I had to apply a tincture on my head. Every morning and evening, and I had to ask my wife to do it for me... I couldn't even see the area myself... I wasn't able to style my hair properly, because this tincture would have been all over it..." (Male participant aged 52 with severe LPP, Germany) • "...I order the shampoo online... and have it delivered at my front door... It's not an inconvenience at all." (Female participant aged 75 with moderate LPP, US)
	Item 19: 'I feel that my knowledge for	<ul style="list-style-type: none"> • "...I still could learn, so 'Sometimes'." (Female participant aged 49 with moderate LPP, US)

Supplementary Table 2: Quotes from qualitative interviews discussing concept relevance for the DLQI, ESS, Scalpdex and OLPSSM

PRO measure	Item	Supporting quotes
	caring for my scalp is adequate.'	<ul style="list-style-type: none"> • "...<i>'All the time'... I know what I have to do.</i>" (Female participant aged 69 with moderate LPP, US)
	Item 20: 'The cost of caring for my scalp condition bothers me.'	<ul style="list-style-type: none"> • <i>"'Often'... it's beginning to get worse... that will probably run me about \$50-\$100 a month."</i> (Female participant aged 72 with moderate LPP, US) • <i>"...that's covered... by the health insurance provider, but even if I would need to pay for it myself it would definitely be worth it... I've never been annoyed by it..."</i> (Female participant aged 63 with moderate LPP, Germany)
	Item 21: 'My scalp condition makes my daily life difficult.'	<ul style="list-style-type: none"> • <i>"... 'Often'... if I'm getting ready... I'm checking the weather. What am I going to be doing? Do I need to throw a hat in the car?"</i> (Female participant aged 55 with moderate LPP, US) • <i>"... 'Never'." Interviewer: "...has your scalp condition ever made day-to-day life difficult?" "No, it has not."</i> (Female participant aged 75 with moderate LPP, US)
	Item 22: 'My scalp condition makes me feel different from others.'	<ul style="list-style-type: none"> • <i>"... 'Often'... either getting ready or I'm getting my daughter's hair ready or, um, with my siblings and their hair is how it used to be."</i> (Female participant aged 55 with moderate LPP, US) • <i>"... 'Never'." Interviewer: "...you've never ever felt like different from others because of your scalp condition?" "No. Nope."</i> (Female participant aged 64 with moderate LPP, US)
	Item 23: 'My scalp condition makes it hard to go to the hairdresser/ barber.'	<ul style="list-style-type: none"> • <i>"... 'Sometimes'... you feel kind of anxious and embarrassed..."</i> (Male participant aged 46 with severe LPP, US) • <i>"... 'Never'... I've actually discussed the topic quite openly, and there are actually other... clients, who have the same problem."</i> (Female participant aged 55 with moderate LPP, Germany)
OLPSSM	Item 1: 'When you <u>brushed your teeth</u> ?'	<ul style="list-style-type: none"> • <i>"...1... There's some slight, uh, tenderness... I have some on my cheeks and then some along my upper and lower gums."</i> (Female participant aged 45 with moderate MLP, US) • <i>"...when you brush your teeth. We're going to go with 'Severely sore'."</i> (Female participant aged 41 with moderate MLP, US)
	Item 2: 'When you <u>ate food</u> ?'	<ul style="list-style-type: none"> • <i>"Any type of food, especially... salt... When they were at their worst, anything made it worse... It could be a piece of gum. Anything hurt it when they were at their worst."</i> (Male participant aged 30 with moderate MLP, US) • <i>"...when you ate food. 1... 'Slightly sore'."</i> (Female participant aged 41 with moderate MLP, US)
	Item 3: 'When you <u>drank liquids</u> ?'	<ul style="list-style-type: none"> • <i>"... 'Severely sore'... Anything. Water, soda, it doesn't matter. If anything touched it, it was just out of control sore."</i> (Male participant aged 30 with moderate MLP, US)

Supplementary Table 2: Quotes from qualitative interviews discussing concept relevance for the DLQI, ESS, Scalpdex and OLPSSM

PRO measure	Item	Supporting quotes
		<ul style="list-style-type: none"> • “...1... liquids that are too hot or carbonated liquids. Soda pop... would, um—it does burn a little bit.” (Female participant aged 45 with moderate MLP, US)
	Item 4: ‘When you <u>smiled?</u> ’	<ul style="list-style-type: none"> • “...that wasn’t, uh, sore at all...” Interviewer: “...has it ever been sore to smile because of your lichen planus...?” “Yes.” (Female participant aged 41 with moderate MLP, US) • “...0.” Interviewer: “...has it ever been sore when you smiled?” “No. I don’t believe so.” (Female participant aged 45 with moderate MLP, US)
	Item 5: ‘When you <u>breathed through your mouth?</u> ’	<ul style="list-style-type: none"> • “...not at all in the past 24 hours... if the ulcers are really bad, breathing through the air, hitting that, it could be moderately sore in the past.” (Female participant aged 45 with moderate MLP, US) • “...I never breathe through my mouth... That’s not much related.” (Female participant aged 73 with moderate MLP, US)
	Item 6: ‘When you <u>talked?</u> ’	<ul style="list-style-type: none"> • “...in the past 24 hours, um, I would say ‘Slightly sore’.” (Female participant aged 45 with moderate MLP, US) • “...0.” Interviewer: “...has it ever been sore when you talked?” “...I don’t believe so.” (Female participant aged 45 with moderate MLP, US)
	Item 7: ‘When it was <u>touched?</u> ’	<ul style="list-style-type: none"> • “...I don’t touch it... if you touch it, it’s too sore...” (Female participant aged 41 with moderate MLP, US) • “When it was touched... it’s not sore at all now, so that would be a 0... but I have experienced that in the past... mostly on my cheeks.” (Female participant aged 45 with moderate MLP, US)

PRO Patient-reported outcome; DLQI Dermatology Life Quality Index; ESS Epworth Sleepiness Scale; OLPSSM Oral Lichen Planus Symptom Severity Measure; LP Lichen planus; CLP Cutaneous lichen planus; LPP Lichen planopilaris; MLP Mucosal lichen planus; US United States; TV Television.

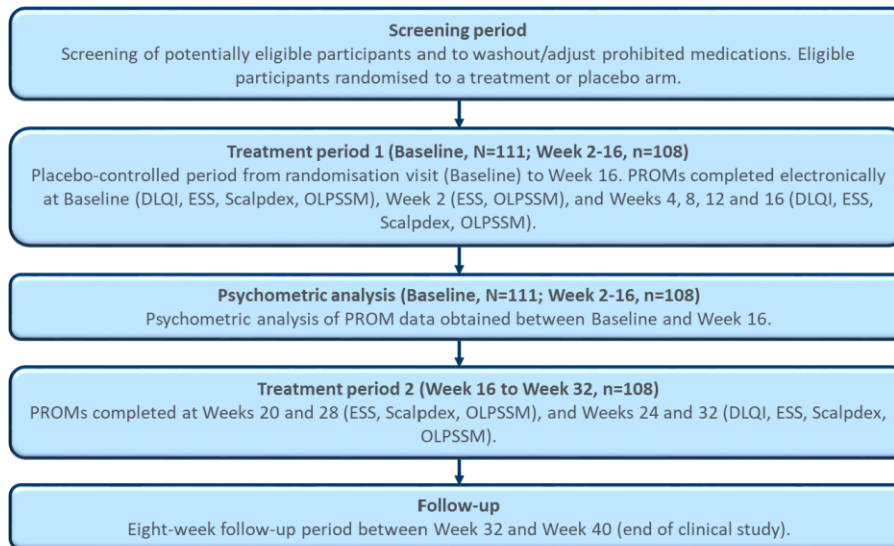


Figure 1. Overview of quantitative phase study design

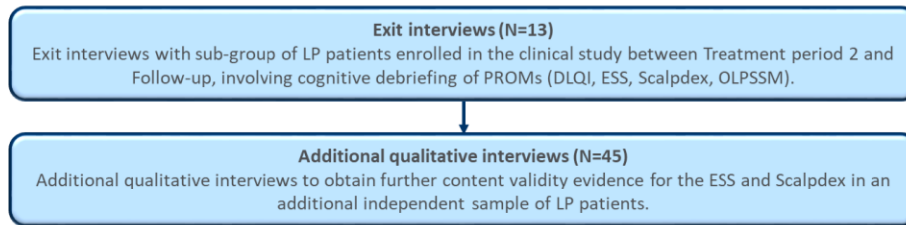


Figure 2. Overview of qualitative phase study design