



# Lichen Sclerosus Survey Results

**November 2018**

# Objectives

- As part of its RareDERM community building initiative, GlobalSkin is working to:
  - Understand the impact of LS on those living with it and if the patient is a child, the effect on them and on their families
  - Determine whether currently available treatments are or are not effective in treating LS from the patient perspective

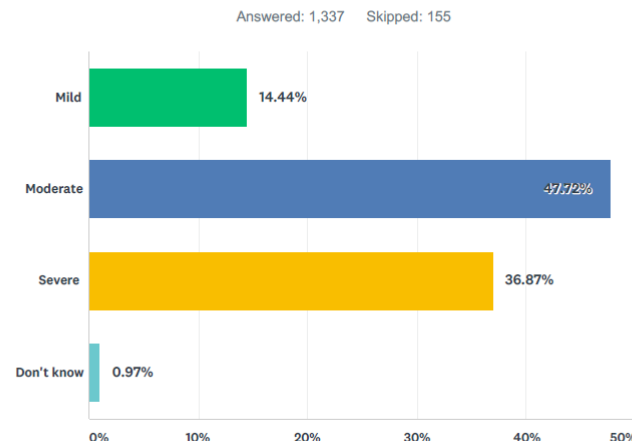


# LS Patient Survey

## Participant profile at a glance:

- N=1492
- 96% females
- 1:1 US:Non-US ratio
- 14% mild
- 48% moderate
- 37% severe
- 92% are receiving treatment
- 63% are receiving standard-of-care
- 77% report to be adherent to treatment ('usually': 42%, 'always' 35%)

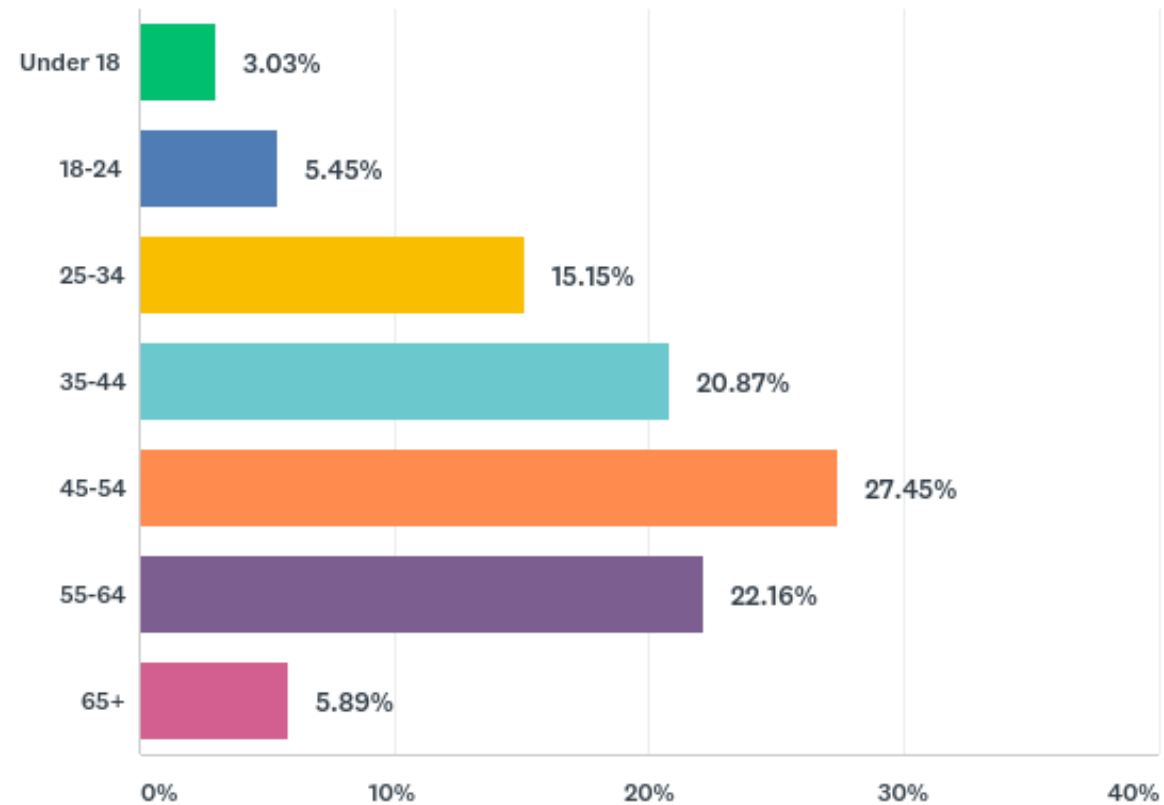
Q37 How would you categorize the severity of your LS condition, based on how it affects your life – the whole you?



ANSWER CHOICES	RESPONSES	
Clobetasol ointment or cream	62.76%	809
Other prescribed topicals (please list):	28.47%	367
Dermovate ointment or cream	26.53%	342
Topical estrogen	22.34%	288
Protopic (tacrolimus)	4.97%	64
Topical testosterone	2.72%	35
Elidel (pimecrolimus)	1.63%	21
Total Respondents: 1,289		

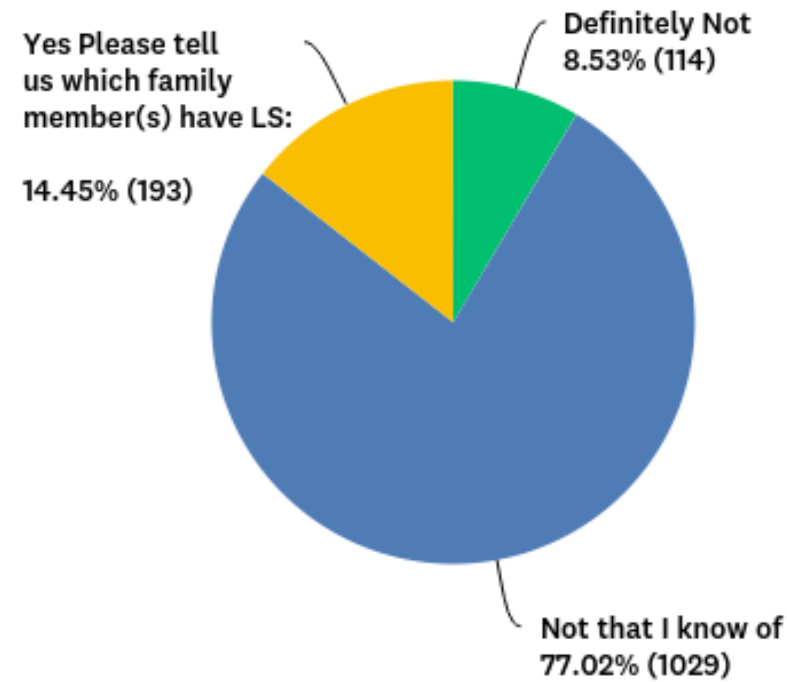
# Patient Profile

Q52 At what age were you diagnosed with LS?



# Patient Profile

Q35 Does anyone else in your family have LS?



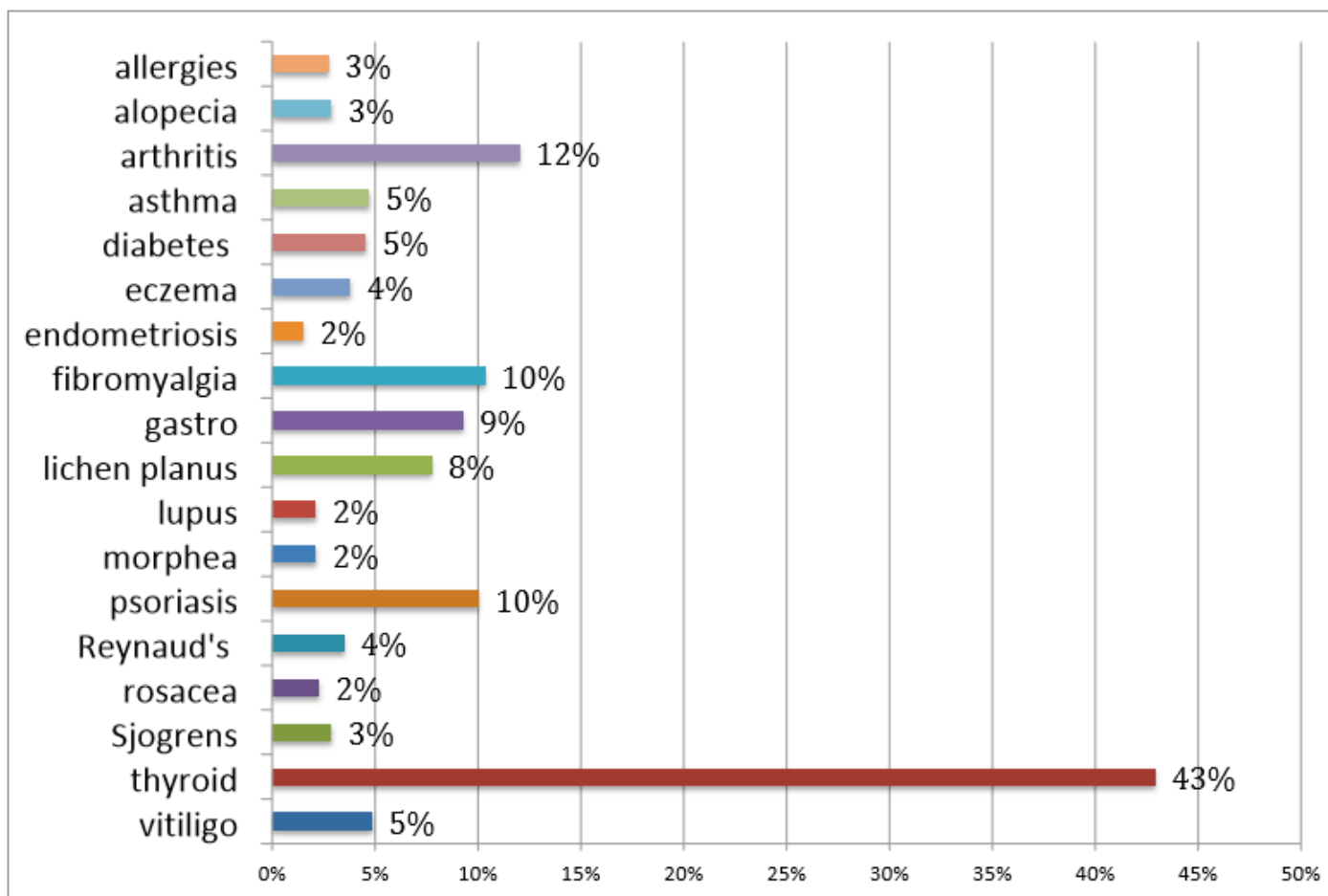
## Family Member

<u>with LS:</u>	<u>Incidence</u>
Mother	44%
Sister	27%
Daughter	10%
Aunt	8%
Grandmother	6%
Cousin	6%
Brother	4%
Father	3%
Niece	1%
Possibly	4%
Not diagnosed	3%

# Patient Profile

N=657 Q. 33 Do you have any other autoimmune diseases? Top replies include:

Condition	Percentage
vitiligo	5%
thyroid	43%
Sjogrens	3%
rosacea	2%
Reynaud	4%
psoriasis	10%
morphea	2%
lupus	2%
lichen pl	8%
gastro	9%
fibromy	10%
endome	2%
eczema	4%
diabetes	5%
asthma	5%
arthritis	12%
alopecia	3%
allergies	3%



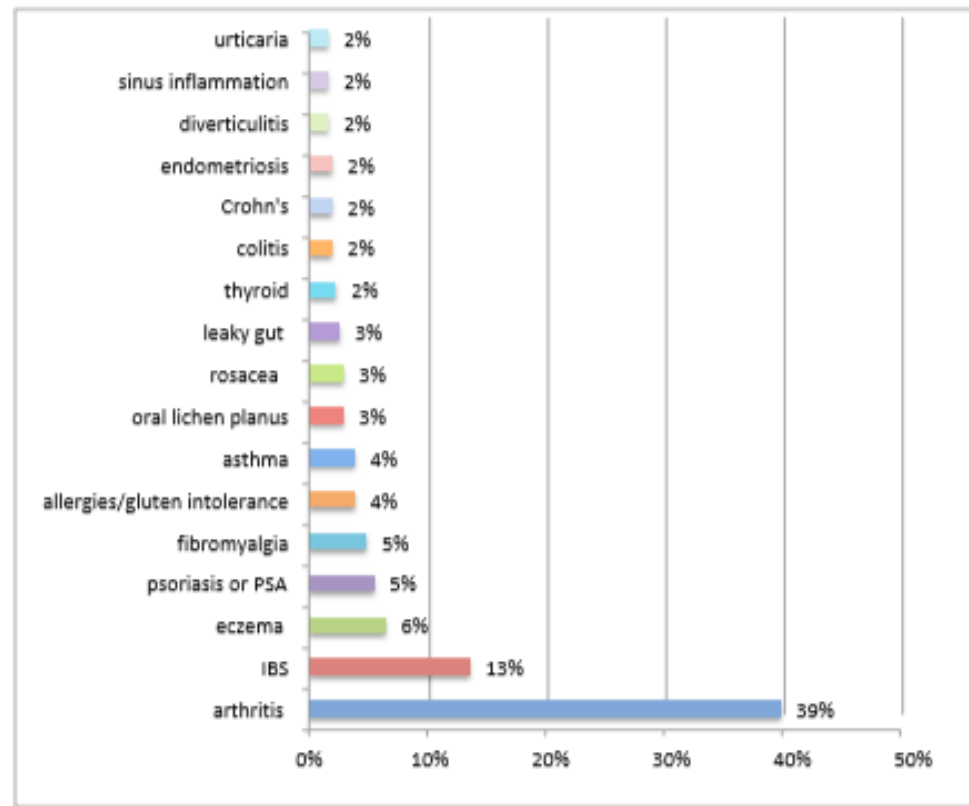
# Patient Profile

Q34 Do you have any other inflammatory diseases? (Please list below.)

Answered: 871 Skipped: 621, assumed No, 556 no responses

Yes: 315

Raw	Has Other Inflammatory Diseases:	Incidence
123	arthritis	39%
42	IBS	13%
20	eczema	6%
17	psoriasis or PSA	5%
15	fibromyalgia	5%
12	allergies/gluten intolerance	4%
12	asthma	4%
9	oral lichen planus	3%
9	rosacea	3%
8	leaky gut	3%
7	thyroid	2%
6	colitis	2%
6	Crohn's	2%
6	endometriosis	2%
5	diverticulitis	2%
5	sinus inflammation	2%
5	urticaria	2%
4	celiac	1%
4	diabetes	1%
3	cystitis	1%
3	GERD	1%
3	morphea	1%
3	Sjogren's	1%
3	vulvodynia	1%
2	adrenal issues	1%
2	breast cancer	1%
2	burning mouth syndrome	1%
2	cfs	1%
2	folliculitis	1%
2	lupus	1%
2	Reynaud's	1%



# LS Overall Impact on QoL

***95% of patients' quality of life impacted***

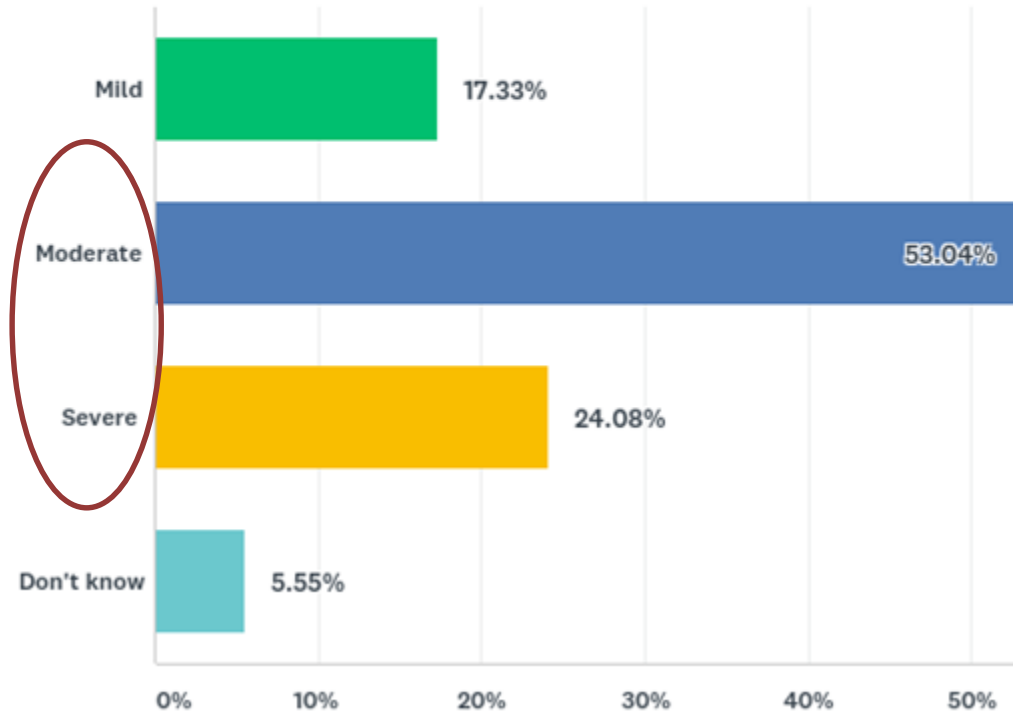
***93% experience sexual impacts***

	NEVER	RARELY	SOMETIMES	FREQUENTLY	ALWAYS	TOTAL	WEIGHTED AVERAGE
Does LS impact the quality of your life?	0.58% 8	4.58% 63	29.48% 406	37.84% 521	27.52% 379	1,377	3.87
Has LS impacted your sexual activities?	2.51% 34	4.35% 59	16.29% 221	27.78% 377	49.08% 666	1,357	4.17

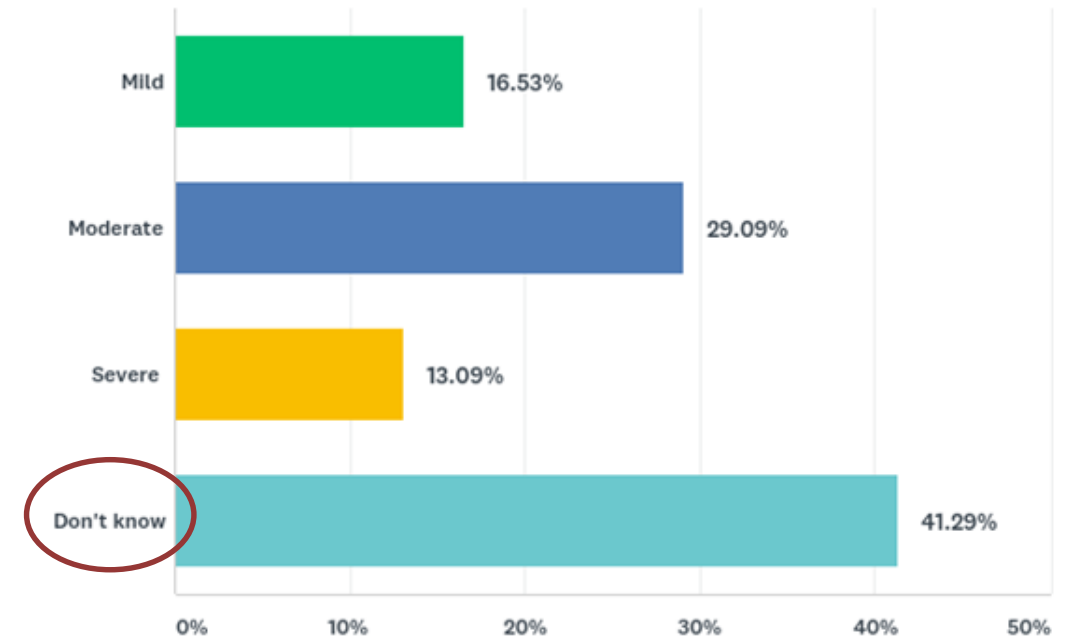


# Severity: Symptoms & Progression

Q36 How would you categorize the severity of your LS condition, based on physical symptoms and progression?

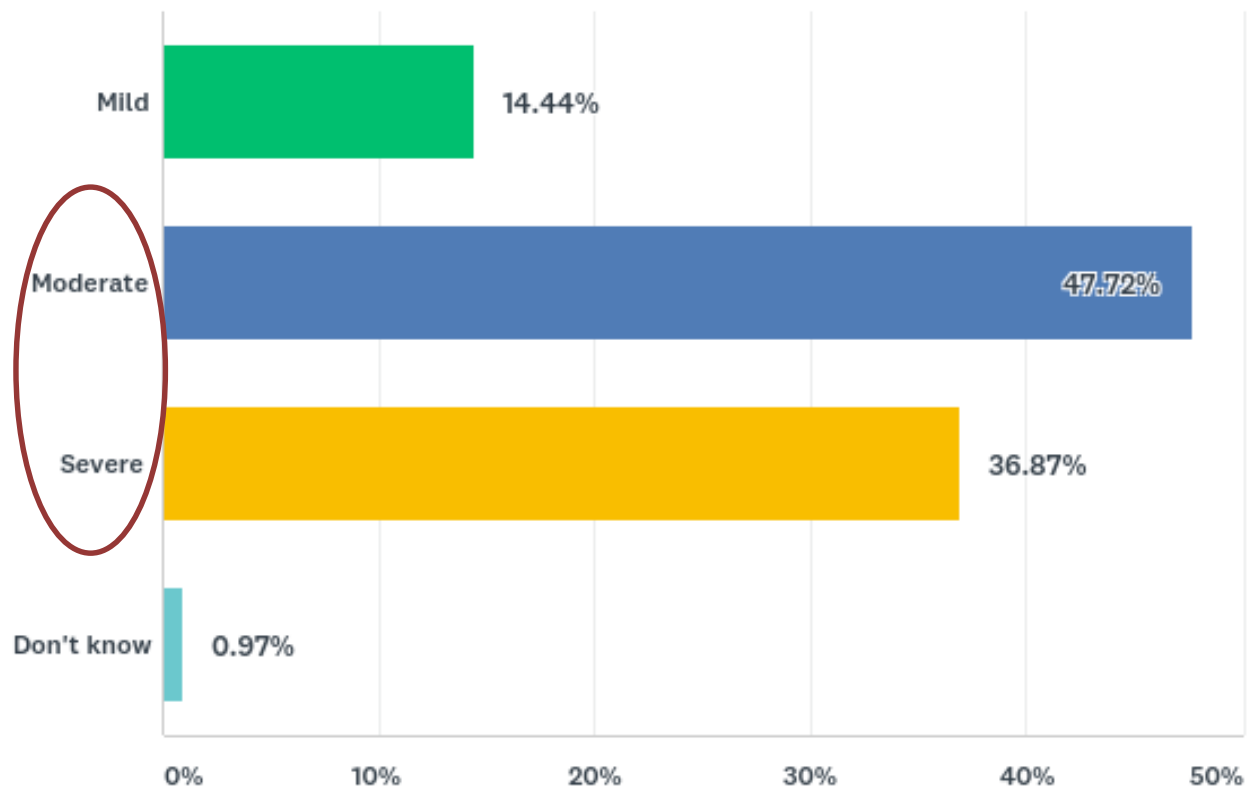


Q38 How does your doctor score your severity of LS?

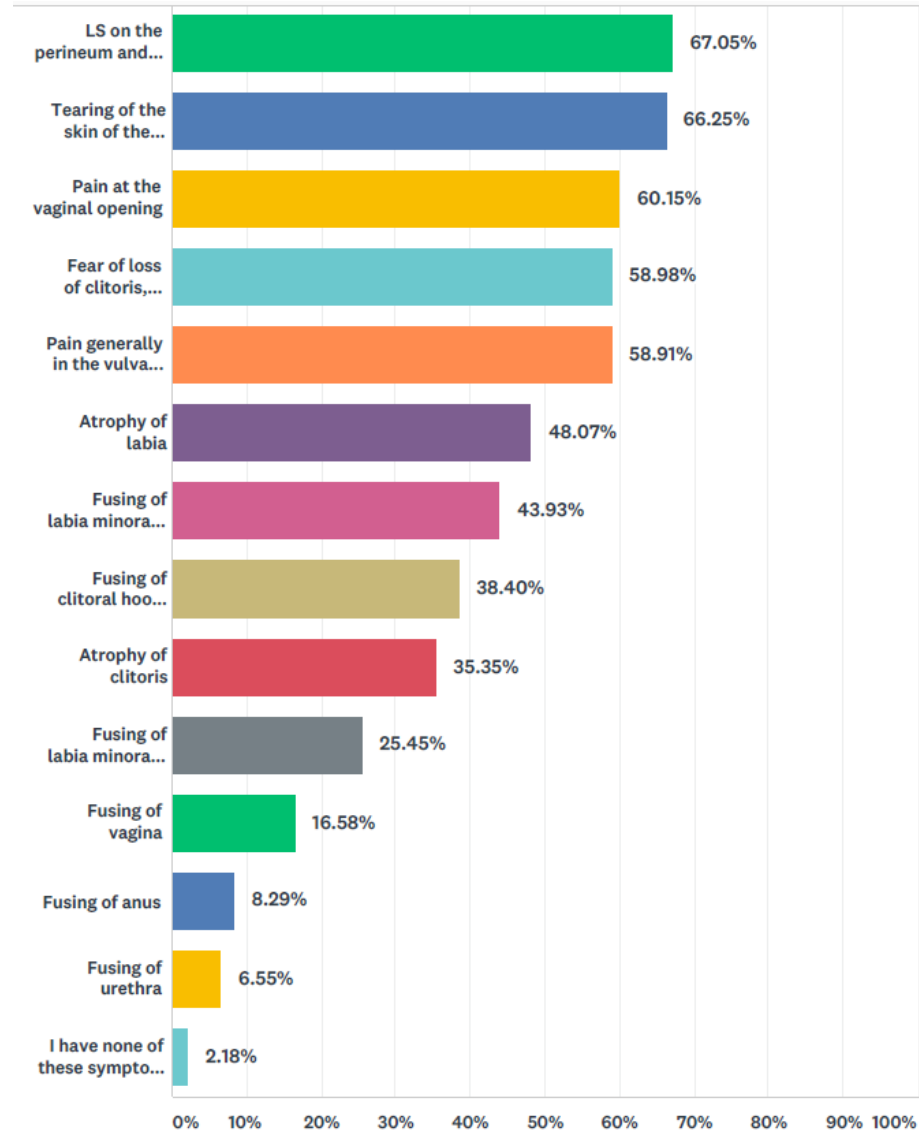
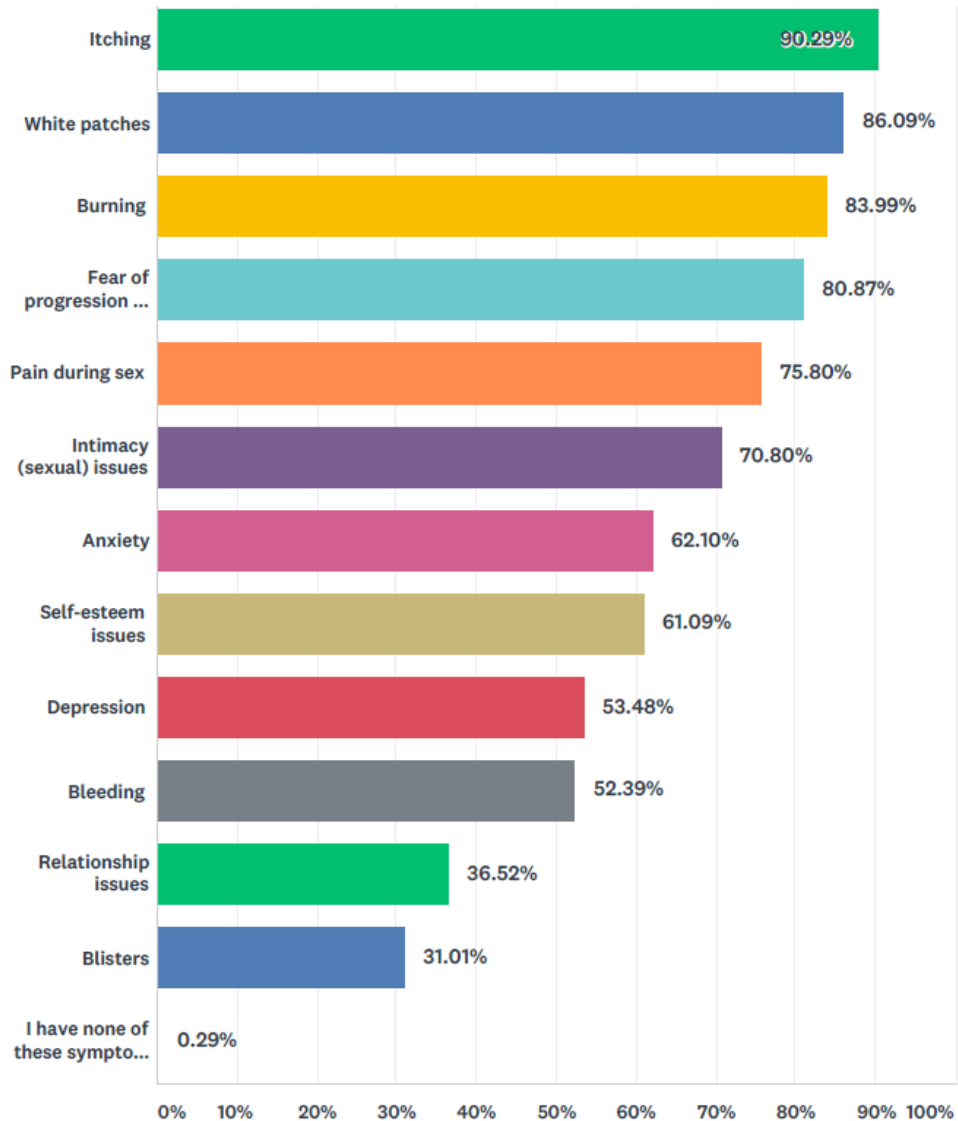


# Severity: Impact on Life

Q37 How would you categorize the severity of your LS condition, based on how it affects your life – the whole you?



# Experienced and Physiological Consequences



# Suicide Ideation

***1 in 10 women** have considered suicide as a consequence of her LS*

***1 in 5 men** have considered suicide as a consequence of his LS*



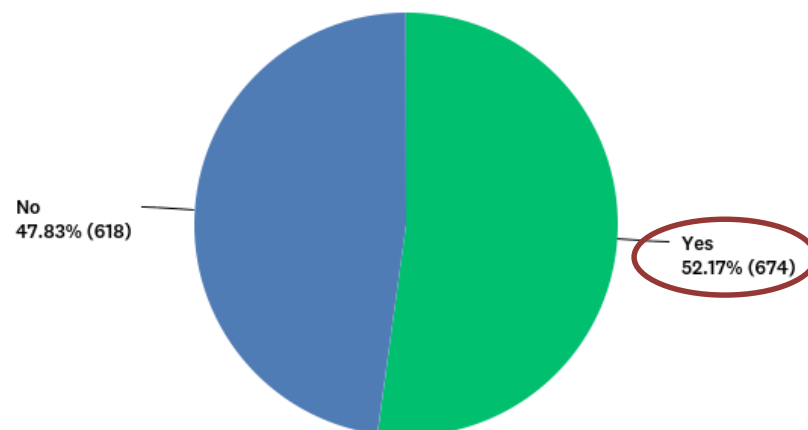
# Physician Care

To what extent are you satisfied with the information about your condition that you received from your doctor?

Answered: 1,136 Skipped: 356

	VERY DISSATISFIED	DISSATISFIED	NEITHER SATISFIED NOR DISSATISFIED	SATISFIED	VERY SATISFIED	TOTAL	WEIGHTED AVERAGE
Extend satisfied 1-5	15.05% 171	31.25% 355	28.35% 322	21.04% 239	4.31% 49	1,136	2.68

Q47 When you were prescribed your treatment(s), did you feel you were given good and thorough instructions on how to use your medication?



46% of patients are dissatisfied with info provided

# Physician Care



*Patients report an average **56 months**  
until they were diagnosed.*

# Disease Management

**Only 21%** of patients are managing their disease well or very well

How well do you feel you are managing your LS condition?

Answered: 1,175 Skipped: 317

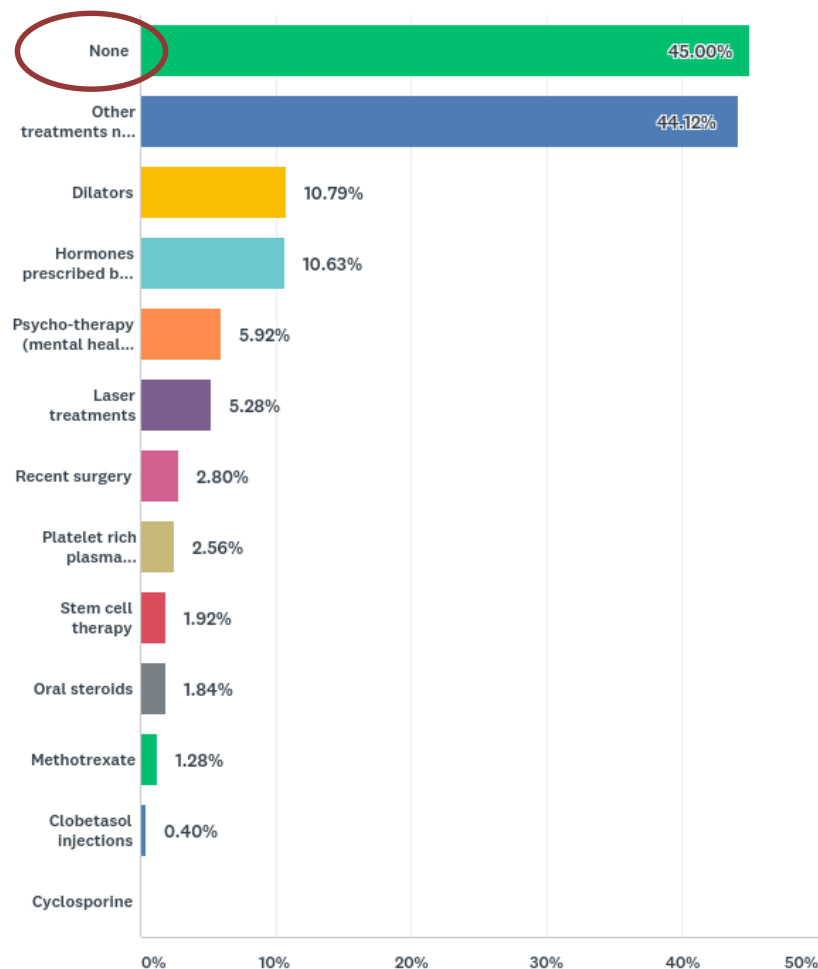
	NOT WELL AT ALL	NOT VERY WELL	OKAY	WELL	VERY WELL	TOTAL	WEIGHTED AVERAGE
How well managing 1-5	5.87% 69	21.87% 257	51.40% 604	15.23% 179	5.62% 66	1,175	2.93

**Only half** of patients have achieved remission.

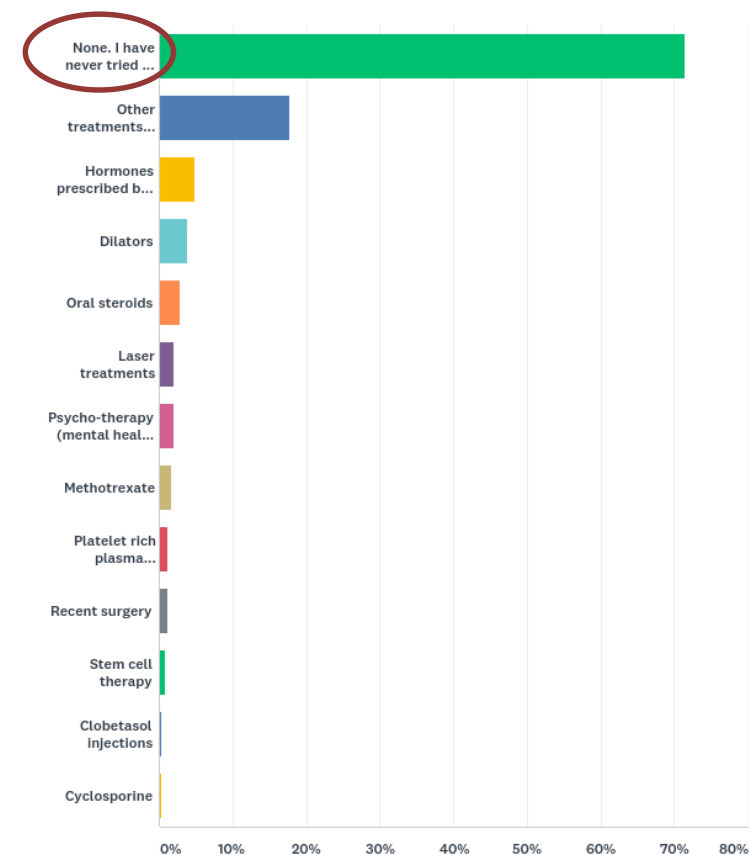
For those who have, the average duration is **7 months**.

# Treatments Used

Q41 Do you use any of the following to treat your LS and its affects on your life? (Please check all that apply.)



Q46 Which if any of the following have you tried in the past that you feel did NOT work well to treat your LS and it affects on your life (may include those currently used)? (Please check all that apply.)

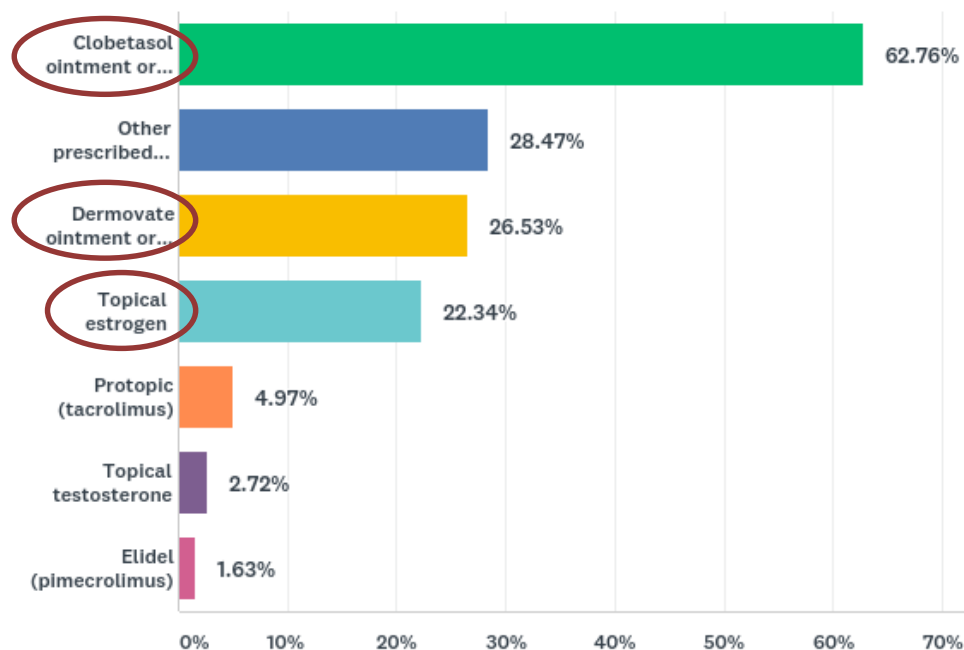




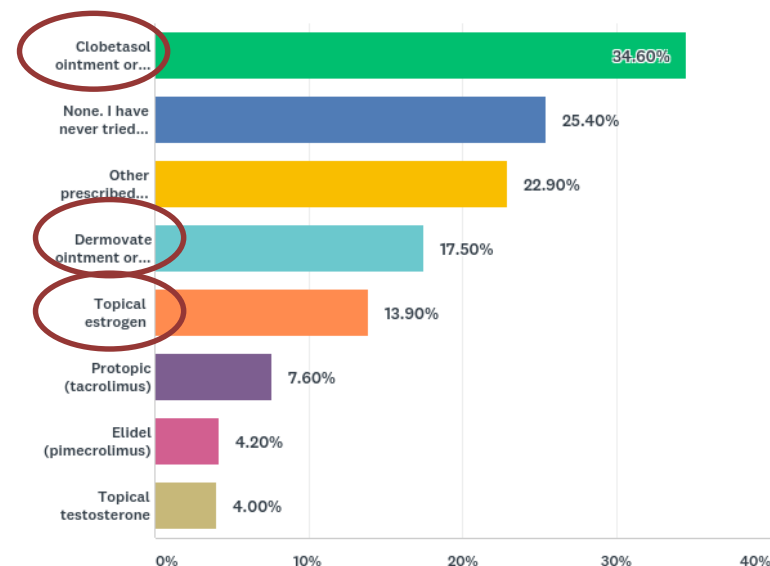
# Topical Treatments Used

*The most used topical is rated the least effective.*

What, if any, topical treatments do you currently use to treat your LS? (Please check all that apply.)



Q45 What, if any, topical treatments have you tried in the past that you feel did NOT work well (may include those currently used)? (Please check all that apply.)



# Treatment Efficacy

How would you rate the efficacy of your current LS treatment?

Answered: 1,313 Skipped: 179

**Over 25%**  
low or very low

	VERY LOW EFFICACY	LOW EFFICACY	NEITHER HIGH NOR LOW EFFICACY	HIGH EFFICACY	VERY HIGH EFFICACY	TOTAL	WEIGHTED AVERAGE
Efficacy Rating 1-5	7.54% 99	18.13% 238	43.34% 569	27.19% 357	3.81% 50	1,313	3.02

How confident are you that your current treatment works?

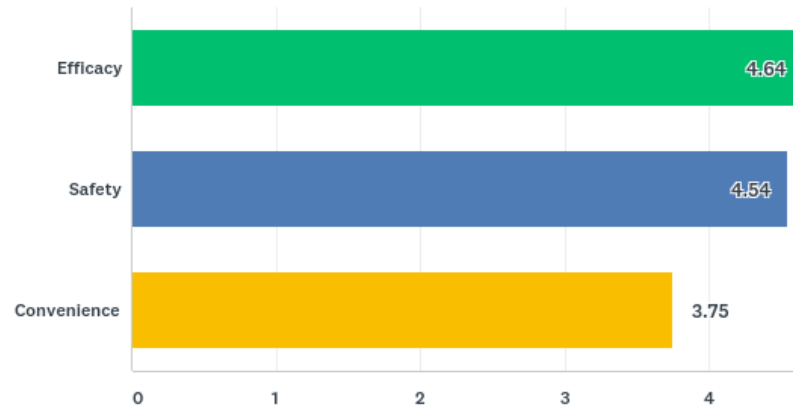
Answered: 1,325 Skipped: 167

**35%** not  
confident

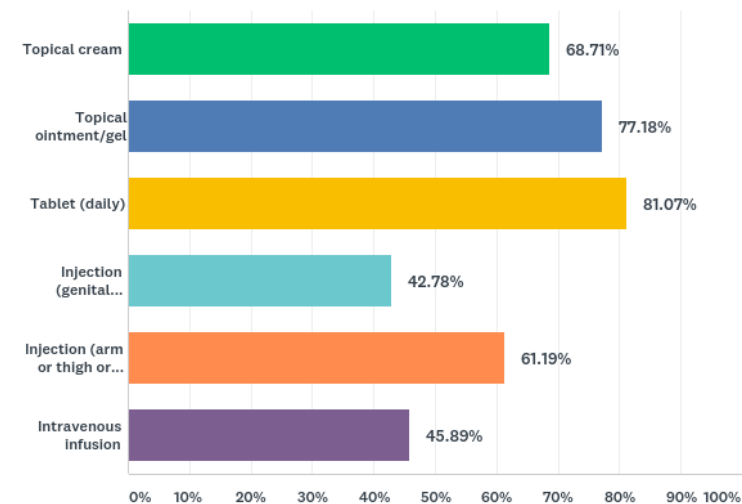
	NOT AT ALL CONFIDENT	NOT SO CONFIDENT	SOMEWHAT CONFIDENT	VERY CONFIDENT	EXTREMELY CONFIDENT	TOTAL	WEIGHTED AVERAGE
Confidence in Treatment 1-5	10.57% 140	25.13% 333	45.81% 607	15.70% 208	2.79% 37	1,325	2.75

# Patient Parameters

Q54 When thinking about a new medication to treat LS, please rate these three factors:

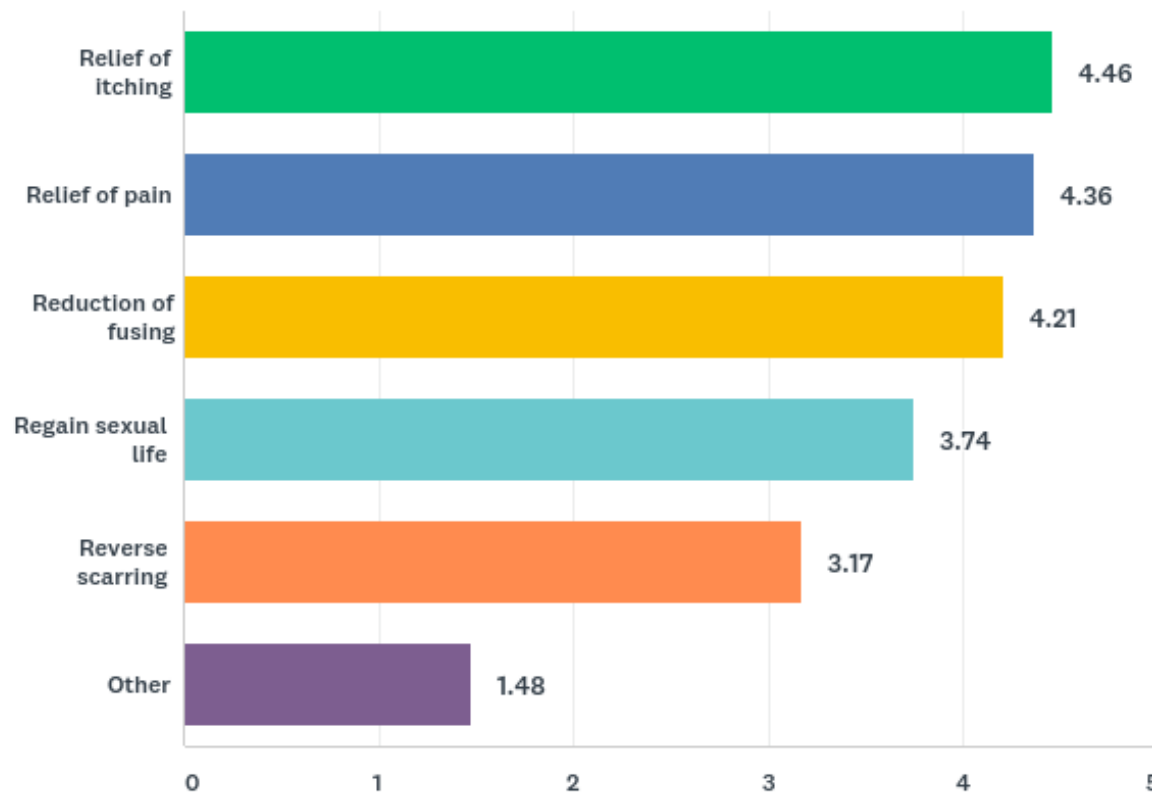


Q55 Using your magic wand again, what delivery form would you be willing to use for a future LS treatment? (Please check all that apply.)



# Patient Parameters

Q57 What would be the most important efficacy parameters in a future treatment? (Rank in order of importance, with 1=top importance.)

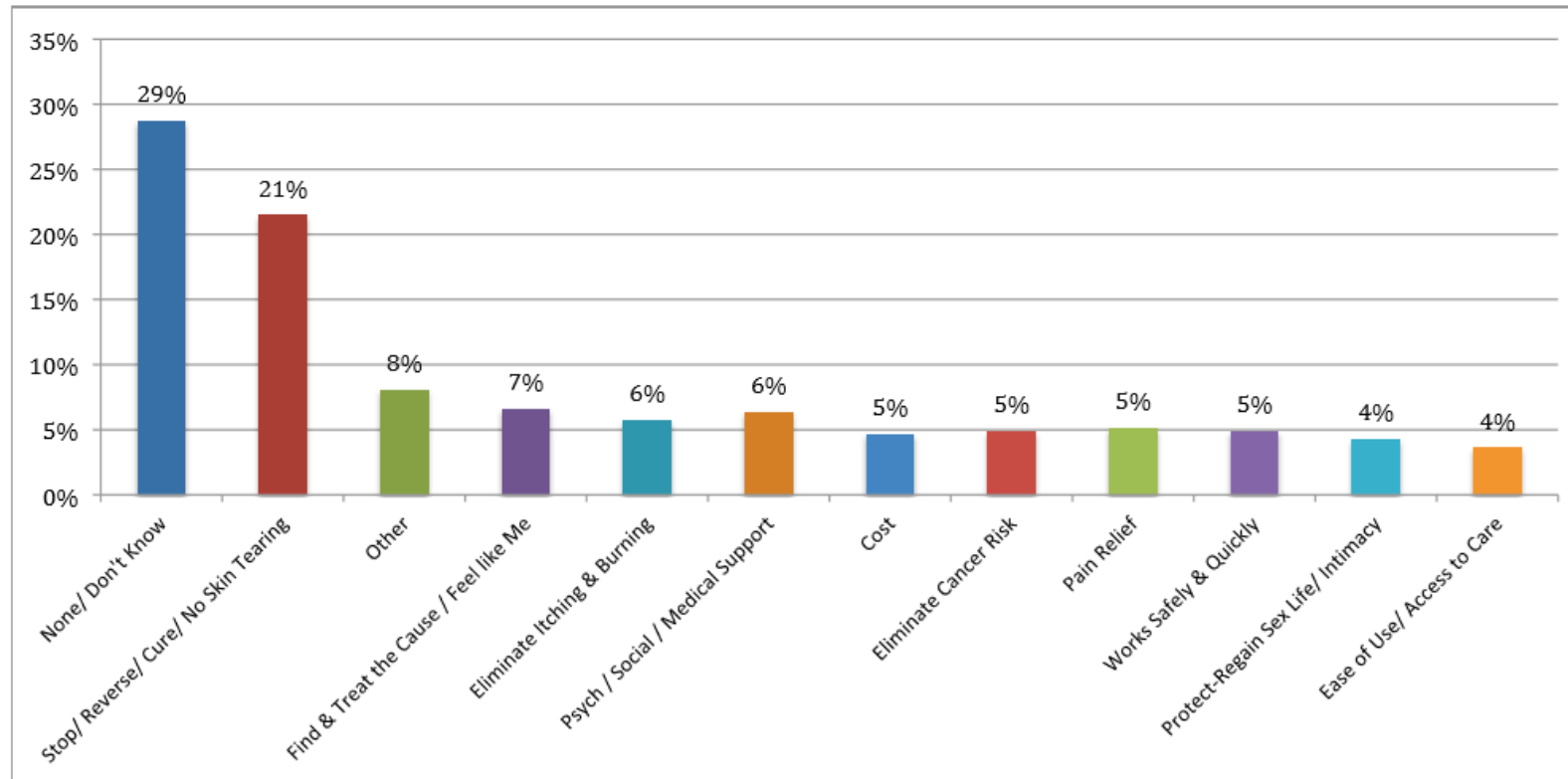


# Other Patient Parameters

Q. 58 Please share any other most important efficacy parameters in a future treatment; please list all:

N= 461

Top Responses :	None/ Don't Know	Stop/ Reverse/ Cure/ No Skin Tearing	Other	Find & Treat the Cause / Feel like Me	Eliminate Itching & Burning	Psych / Social / Medical Support	Cost	Eliminate Cancer Risk	Pain Relief	Works Safely & Quickly	Protect- Regain Sex Life/ Intimacy	Ease of Use/ Access to Care
Incidence:	29%	21%	8%	7%	6%	6%	5%	5%	5%	5%	4%	4%

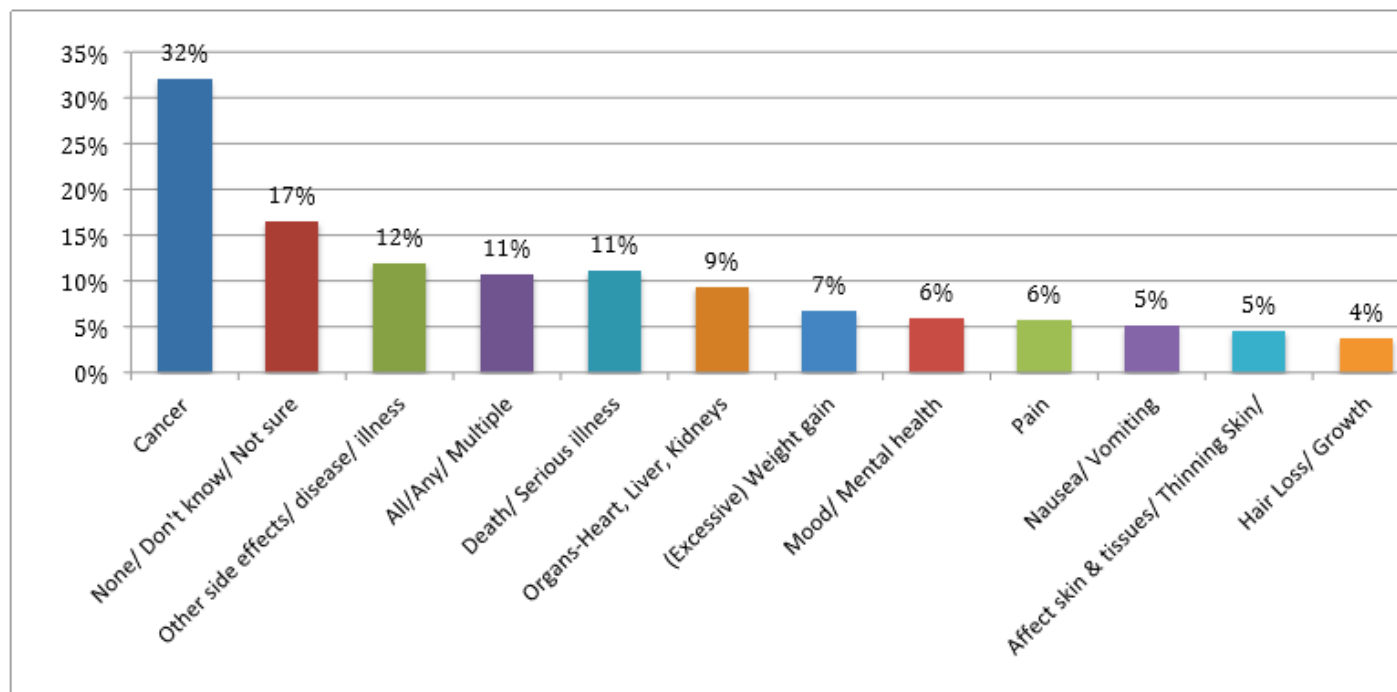


Two per cent said they would not use anything. Another 1% or less mentioned ease of application (i.e., not fingers, help from mirror on stick); being able to wear any clothing and resume activities; no worsening side effects.

# Patient Parameters

Q.56 What risks and/or side-effects would stop you from taking a medication that could have N=969

Top Responses over 3%:	Cancer	None/ Don't know/ Not sure	Other side effects/ disease/ illness	All/Any/ Multiple	Death/ Serious illness	Organs- Heart, Liver, Kidneys	(Excessive) Weight gain	Mood/ Mental health	Pain	Nausea/ Vomiting	Affect skin & tissues/ Thinning Skin/ Damage to skin	Hair Loss/ Growth
	32%	17%	12%	11%	11%	9%	7%	6%	6%	5%	5%	4%



Maternal/ fetal/fertility; Migraine/headaches; Affect sex life; Burning/ Blistering; Quality of Life; Gastro/ Stomach; Itch, Neuro/ Nerve  
3% or less: damage; Risks/ Safety; Bleeding or clotting; Cost

# Patient Comments

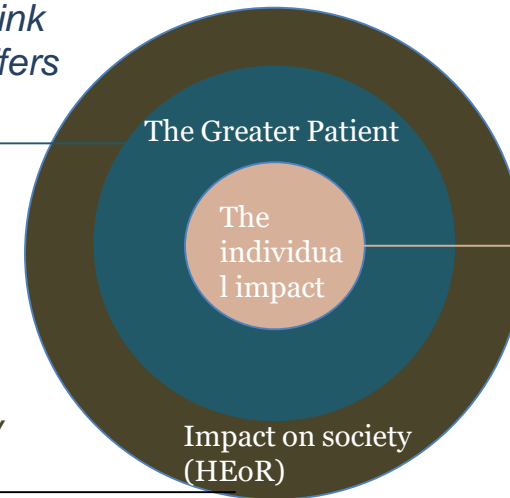


***This disease affects us as women.  
What makes us women.  
The part of us that is woman.***

*My husband is a saint  
and has been true to  
me. I suffer from this  
disease, but I think  
my husband suffers  
more.*

*LS has  
robbed me of  
being a fully  
functioning  
woman, wife  
and mother.*

*I can't work today..my  
private parts hurt.*



# Conclusions

- LS is an overlooked and under served disease
- There is a significant hidden population fueled by shame and symptoms that are often not well managed
- Its effects are frequently permanent
- The disease defines to how patients view themselves

