

Vulvar Lichen Sclerosus Severity Scale

Welcome to the Adult Vulvar Lichen Sclerosus Severity Scale Survey

Thank you so much for agreeing to participate in this survey. Your expert opinion will contribute to shaping a severity scale for use clinically and in research regarding vulvar lichen sclerosis. This process will be completed through the use of a Delphi exercise wherein you will be asked for your responses to our survey today, as well as 2 weeks from now and 4 weeks from now. Each survey should take no more than 10-15 minutes to complete. The items included in this first survey were selected based on an extensive literature review of all clinical trials which have been done with regards to vulvar lichen sclerosis treatment. Between each iteration of the survey, our research team will be in touch to update you as far as the expert consensus so far to make you aware of the general opinion. If you have any questions, please feel free to address them to the principal investigator: Dr. Amanda Selk: amanda.selk@utoronto.ca.

Please read the consent letter which was emailed to you in your invitation to participate in this survey. By choosing to move forward with the survey, it will be understood that you consent to participate in this research.

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* 1. What is your gender:

- Male
- Female

* 2. What is your main field of practice?

- Dermatology
- Gynecology
- Pathology
- Genitourinary medicine
- Sexual Medicine
- Nurse Practitioner
- Family Doctor/ General Practitioner
- Other (please specify)

* 3. Where do you practice? (Please specify a country e.g. USA, Australia, England, China, etc):

* 4. How long have you been in practice?

- Less than 5 years
- 6-10 years
- 11-15 years
- 16-20 years
- Greater than 20 years

* 5. Are you a member or a fellow of the ISSVD?

Member

Fellow

Other (please specify)

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* 6. When you are assessing the severity of adult vulvar lichen sclerosus, please rate the importance of each of the following PATIENT REPORTED symptoms on a scale of 1 (not important) to 5 (essential)

	Not important at all	Not very important	Somewhat important	Very important	Essential
Itch	<input type="radio"/>				
Irritation	<input type="radio"/>				
Dryness	<input type="radio"/>				
Pain unrelated to intercourse (burning, soreness, discomfort, etc.) at rest or during activity	<input type="radio"/>				
Pain with intercourse	<input type="radio"/>				
Skin tearing with intercourse	<input type="radio"/>				
Difficulty urinating (dribbling, having to stand up to void)	<input type="radio"/>				
Difficulty with bowel movements (constipation)	<input type="radio"/>				

Other (please specify)

* 7. How should these symptoms be measured?

- Presence or absence of symptoms (e.g. Yes/No)
- Severity scale (e.g. 5-point Likert: 1 absent/never, 2 sometimes/occasionally, 3 often, 4 most of the time, 5 all the time)
- Other (please specify)

* 8. When you are assessing the severity of adult vulvar lichen sclerosus, please rate the importance of these other PATIENT REPORTED symptoms on a scale of 1 (not important) to 5 (essential)

	Not important at all	Not very important	Somewhat important	Very important	Essential
Changes/decrease in sexual function	<input type="radio"/>				
Mood changes (depression/anxiety)	<input type="radio"/>				
Quality of Life	<input type="radio"/>				

* 9. How should these other symptoms (sexual function, mood, quality of life) be measured?

- Presence or absence of symptoms (e.g. Yes/No)
- Severity scale (e.g. 5-point Likert: 1 no impact, 2 barely affected, 3 slightly affected, 4 moderately affected, 5 strongly affected)
- If patient screens positive and answers yes to symptoms, use appropriate existing scale to measure if required (e.g. female sexual function index, dermatology quality of life index)

Other (please specify)

* 10. Patients should be asked about their symptoms over what time period i.e. over the past week/month/year? An example would be: "Over the past month, please rate how often you feel the following: itch"

- Week
- Month
- 3 months
- 6 months
- 1 year
- Other (please specify)

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* 11. When determining the severity of adult vulvar lichen sclerosus, consider the following signs on physical exam, and please rate each sign's importance on a scale of 1 (not important) to 5 (essential).
 (note: if you are unclear as to the meaning of a specific term - please take this into consideration when rating it's importance in determining disease severity)

	Not important at all	Not very important	Somewhat important	Very important	Essential
Erosions	<input type="radio"/>				
Fissures	<input type="radio"/>				
Ulcerations	<input type="radio"/>				
Hyperkeratosis	<input type="radio"/>				
Telangiectasia	<input type="radio"/>				
Petechiae	<input type="radio"/>				
Ecchymosis	<input type="radio"/>				
Colour (normal vs abnormal)	<input type="radio"/>				
Pallor	<input type="radio"/>				
Hypopigmentation	<input type="radio"/>				
Erythema	<input type="radio"/>				
Whitening	<input type="radio"/>				
Crinkly/fine wrinkling of skin/parchment-like skin	<input type="radio"/>				
Excoriations	<input type="radio"/>				
Lichenification	<input type="radio"/>				
Induration	<input type="radio"/>				
Elasticity (or loss of elasticity)	<input type="radio"/>				
Sclerosis	<input type="radio"/>				
Edema	<input type="radio"/>				
Atrophy	<input type="radio"/>				

Not important at all Not very important Somewhat important Very important Essential

Extent of disease (figure of eight vs. localized to labia, localized to clitoris, localized to the perineum or combined.)

Whether the disease is symmetrical vs. asymmetrical

Other (please specify)

* 12. How should these clinical signs be measured?

- Presence or absence of signs (e.g. Yes/No)
- Severity (for example: mild, moderate, severe for each sign)
- Other (please specify)

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* 13. When you see the following signs (those you have selected as being somewhat important, very important, or essential on the previous question), do you consider that sign to be a marker of mild, moderate or severe disease?

	Mild	Moderate	Severe
Erosions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fissures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ulcerations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hyperkeratosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telangiectasia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Petechiae	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ecchymosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Colour (normal vs abnormal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pallor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hypopigmentation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Erythema	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whitening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Crinkly/fine wrinkling of skin/parchment-like skin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Excoriations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lichenification	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Induration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elasticity (or loss of elasticity)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sclerosus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Edema	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Atrophy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Extent of disease (figure of eight vs. localized to labia, localized to clitoris, localized to the perineum or combined.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Mild

Moderate

Severe

Whether the disease is
symmetrical vs.
asymmetrical

Other (please specify)

* 14. When determining the severity of adult vulvar lichen sclerosis, consider the finding of **architectural changes/anatomical distortion** on physical exam, and please rate this finding's importance on a scale of 1 (not important) to 5 (essential)

Not important at all

Not very important

Somewhat
important

Very important

Essential

Architectural
changes/anatomical
distortion

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* 15. When architectural changes/anatomical distortion are present on physical exam, please rate each particular change's importance on a scale of 1 (not important) to 5 (essential)

	Not important at all	Not very important	Somewhat important	Very important	Essential
Clitoral hood fusion	<input type="radio"/>				
Labial fusion/resorption	<input type="radio"/>				
Narrowing of the introitus	<input type="radio"/>				
Anterior changes	<input type="radio"/>				
Posterior changes	<input type="radio"/>				

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* 16. When you see the following architectural changes (those you have selected as being somewhat important, very important, or essential on the previous question), do you consider that sign to be a marker of mild, moderate or severe disease?

	Mild	Moderate	Severe
Clitoral hood fusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Labial fusion/resorption	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Narrowing of the introitus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anterior changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Posterior changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 17. How should architectural changes/anatomical distortion be measured?

- Presence or absence of that change (for example: Yes or No)
- Severity (for example: mild, moderate, or severe for that change)
- Other (please specify)

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18. Thank you so much for participating! Please remember that we will be emailing you with the 2nd survey of 3 in 2 weeks time.

Please feel free to suggest other items you'd like us to incorporate into future surveys.

Please feel free to provide us comments.