

## Summary of findings from the Living with Vulval Lichen Sclerosus Interview Study

**What was the study about?** Vulval lichen sclerosus is a chronic condition which can have a huge impact on everyday life and self-identity. There is very little research about the experience of living with vulval lichen sclerosus from the perspective of people with the condition.

**What was the aim of the study?** To talk to people to understand their experiences of living with vulval lichen sclerosus and its impact on their lives.

**What did we do?** We advertised the study on online support groups and social media. We interviewed 20 women (by telephone or a video call) with vulval lichen sclerosus living in the UK.

**What did we find out?** We developed three themes to explain the women's experiences of living with vulval lichen sclerosus:

1. **Missed opportunities** which included:
  - a) Difficulties or delays in getting a diagnosis or being diagnosed with something other than vulval lichen sclerosus e.g., thrush, menopause.
  - b) Being dismissed by doctors or healthcare professionals.
  - c) Doctors and healthcare professionals not knowing what vulval lichen sclerosus is.
  - d) Not getting any or enough information about what vulval lichen sclerosus is and how to manage it.
  
2. **Learning to live with a long-term condition** which included:
  - a) The emotions associated with getting a diagnosis of vulval lichen sclerosus e.g., relief, happiness, shame, fear, anger, and shock.
  - b) Doing their own research or finding information from the internet or support groups.
  - c) Deciding when and how often to use their steroid treatment or whether they should have follow-up care because they had been given different advice by different people.
  - d) It can take a lot of work to self-manage vulval lichen sclerosus.
  
3. **A secret life** which included :

- a) The difficulty talking to other people about vulval lichen sclerosus because they do not know what it is and they worry about how other people will react.
- b) Feeling lonely or isolated because of not having many people to talk to about it and the stigma about the vulva.
- c) The help they got from support groups which made them feel like they were not the only going through this.
- d) A loss of identity or femininity because their body had changed.

**Our conclusions:** People attending their doctor with vulval complaints should be examined and lichen sclerosus should be considered as a diagnosis. Healthcare professionals' awareness and knowledge of vulval lichen sclerosus needs to be improved and they should avoid language which criticises or dismisses the patients' experiences. Vulval lichen sclerosus is a chronic condition and patients need to be supported in self-management. Support groups may be a source of support and information but can also be challenging when hearing others' difficult experiences. Wider public health educational activities are needed to change societal attitudes towards female genitals and tackle the stigma around vulval conditions.

**What's next?** We are publishing our findings in academic journals and sharing them at conferences. We want healthcare professionals to hear about what it is like to live with LS, and how they might be able to improve patient experience. We are producing an animated video to share the findings, aimed at healthcare professionals. We are also doing a questionnaire study through general practice, to see if what we found in these interviews is also reflected in a larger group of patients who may not be accessing support groups. We are planning future research informed by our findings.

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**THANK YOU FOR TAKING PART!**