Thank you for taking part in our survey about laser treatment for vulval lichen sclerosus (LS)

Please read the information below if you would like to hear about our findings.

Why did we do this study?
LS is a debilitating long-term condition that affects the outer genital (vulval) skin in 3% of women. Symptoms include pain and itch. LS causes sticking together (scarring) of the vulval skin in 60% of affected women.

The recommended treatment for LS is a strong steroid cream or ointment applied to the vulva. 70% of women respond to this treatment but scarring can still occur. There is no strong evidence to guide which treatments should be tried after steroid creams.

Laser is a potential new treatment which is not currently available in the NHS. We asked the following groups to tell us what they think about this potential new treatment:

- females with LS
- representatives of females who have LS
- healthcare professionals who treat females with LS

We needed to understand the views of these groups for planning future research, so that studies have a higher chance of success.

What did the study involve?
LS support groups kindly shared this online survey on social media – this meant that people filled it in from all over the world! A separate survey was emailed to health professionals via the British Society for the Study of Vulval Disease (BSSVD) and also shared on social media.

Results of the study

248 patients

9 patient representatives

56 health professionals

14 countries

July 2021

Patient survey: key findings

- 58% of patients and 33% of representatives **knew nothing about laser for LS**
- 14% of patients **had received treatment with laser for LS**, or knew someone else who had
- 36% of patients and 50% of representatives were **worried about the risks of laser treatment**
- 25% of patients and 33% of representatives would **consider taking part in a future laser study**

Health professional survey: key findings

- 80% had treated patients who **did not respond to first line treatment** (topical steroids)
- 7% had **administered laser for LS**, 12% had treated patients who had received laser for LS in the past
- 52% thought the **evidence for laser in LS was low or very low**
- 23% agreed to some extent that **laser could be useful in LS**
- 43% were **concerned about the risks of laser** treatment for patients
- 63% said they would **consider entering their patients into a future laser study**

These findings were presented at the BSSVD annual meeting in May 2021.

What does this mean?

- Patients and health professionals agree that high-quality evidence is needed to support laser as a potential treatment for vulval LS
- LS has a huge impact on all aspects of women's lives and more evidence for treatment options is desperately needed
- Many patients and health professionals would consider entering a future study testing laser for LS
- Barriers to the use of laser and study design will need to be carefully considered to ensure the success of a future study

What happens now?
Before setting up a large study, it is important to find out if laser is a treatment that patients will want to have and if it is practical to introduce into the NHS. The information from this survey has been used to help design a small feasibility study – this will tell us if a large 'definitive' trial is possible. We are grateful to all those who shared and participated in this study. For updates on our ongoing work in this area and opportunities to take part in future projects, please visit the vulval and genital conditions page of the Centre of Evidence Based Dermatology website.

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