

# Patient power sets top research priorities for lichen sclerosis

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People with a distressing skin condition have had their say in which

aspects of the disease should be prioritised in future medical research.

Lichen sclerosis is an inflammatory [skin condition](#) affecting the genital area that causes a variety of symptoms including severe itching, pain and splitting of the skin in these sensitive areas.

Now, a partnership led by University of Nottingham experts has revealed the top 10 questions that should be the focus of new research, according to people who have lived with this difficult to manage condition, or those that have been involved in its [treatment](#).

Leading the Lichen Sclerosis Priority Setting Partnership, Dr. Rosalind Simpson from the University's Centre of Evidence Based Dermatology, said: "Despite the fact that lichen sclerosis can make life miserable for at least 1% of women and probably similar proportion of men, this is an under-funded and under-researched medical problem. There is considerable need for further understanding of this condition as well as for improved knowledge and awareness amongst the public and the wider medical community."

A patient who took part in the research priority setting said: "I feel honoured to have been on the steering group for this work which has given [patients](#) a rare opportunity to shape the research agenda for this little understood, yet devastating condition. I felt that my input was valued as much as that of the professionals on the group which was very empowering. I am hopeful that the findings will lead to more research in this area and ultimately to earlier diagnosis, better treatment options and perhaps even prevention of lichen sclerosis. It is very heartening to see such a focus on what is often a 'hidden' disease and I hope that the Priority Setting Partnership also raises awareness of the signs and symptoms amongst professionals and the public."

Around 650 patients, carers, relatives or health professionals submitted

more than 2,500 questions to the initial survey and additional questions were gathered from three key systematic reviews and existing guidelines in the scientific literature. Out of these, 38 unique questions were identified that had not already been answered by research.

A second online survey, completed by 954 people, identified a shortlist of 23 most important questions. These were then discussed by a range of patients and health professionals at a face-to-face workshop at which the final 'top 10' Research Priorities were established.

The Top 10 [questions](#) identified are as follows:

1. What is the best way to prevent and manage anatomical changes caused by lichen sclerosis?
2. What is the best way to diagnose lichen sclerosis (diagnostic criteria)?
3. What surgical treatments should be offered for lichen sclerosis?
4. Are there effective topical treatments other than topical steroids in the treatment of lichen sclerosis?
5. What is the risk of developing cancer in patients with lichen sclerosis?
6. Which aspects of lichen sclerosis should be measured to assess response to treatment?
7. Can lichen sclerosis be prevented from occurring and what are the trigger factors?
8. Is it necessary to continue treatment for patients with lichen sclerosis who do not have any symptoms and/or signs of disease activity?
9. What is the impact on quality of life?
10. Does the disease course of lichen sclerosis differ in boys and girls, adult males and females?

The full report is now available [online](#) and has also been published as a

research paper in the *British Journal of Dermatology*. The work also highlighted a lack of general knowledge and awareness of [lichen sclerosis](#) among [health professionals](#) and the wider public.

**More information:** R.C. Simpson et al. Future research priorities for lichen sclerosus – results of a James Lind Alliance Priority Setting Partnership, *British Journal of Dermatology* (2018). [DOI: 10.1111/bjd.17447](#)

Provided by University of Nottingham

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