



Lichen Sclerosus Priority Setting Partnership Newsletter

It has been just over a year since we completed the Lichen Sclerosus Priority Setting Partnership (LS-PSP). We have been working hard to share the results and start addressing these priorities. The aim of this brief newsletter is to update those who participated in the project on the progress that has been made.

Publications

We've produced a report that details the Priority Setting Partnership from start to finish. Prefaced with an 'easy read' Executive Summary, the report contains background information about the project, the methods we used, and provides a full account of the results. [The Priority Setting Partnership Final Report](#) can be downloaded from the JLA website.

We've also published the results in the British Journal of Dermatology. This is the official journal of *British Association of Dermatologists*, and one of the top dermatology journals in the world. The article [Future research priorities for lichen sclerosus – results of a James Lind Alliance Priority Setting Partnership](#) can be downloaded free of charge from the journal website.

Conferences

Rosalind Simpson, lead of the Lichen Sclerosus Priority Setting Partnership, has presented the results at a number of international medical conferences to raise awareness of the Top Ten priorities for Lichen Sclerosus. These presentations have also led to discussions on how to address these questions using research.

- British Society for the Study of Vulval Disease Annual Meeting - May 2019 (Warwick, UK)
- World Congress of Dermatology Meeting - June 2019 (Milan, Italy)
- Royal College of Obstetricians and Gynaecologists World Congress - June 2019 (London, UK)

Impact

>> Dr Sophie Rees, a researcher at the University of Warwick has started work on the Top 10 Question 'What is the impact on quality of life?' Sophie led a systematic literature review to identify studies exploring the lived experience of vulval lichen sclerosus. The review found only three studies, but these did provide some insight into the experience of patients with vulval lichen sclerosus. More research is needed to examine the unmet needs and care pathways of women with Lichen Sclerosus. Sophie has published her findings in the British Journal of Dermatology and plans to continue work in this field.

>> Responses the Lichen Sclerosus Priority Setting Partnership have been used to establish what aspects of the disease are most important to patients and healthcare professionals. Charlotte Goodrum, a medical student at the University of Nottingham analysed over 1500 pieces of free text data from 653 participants. Charlotte's work showed 6 core areas:

- quality of life
- appearance
- fear of progression
- sexual dysfunction
- discomfort from symptoms
- management

Impact (continued)



>> Dr Rosalind Simpson (pictured left) has received a monetary 'pump-priming' award from the UK Dermatology Clinical Trials Network (UK DCTN) to fund further research for Lichen Sclerosus.

The £10,000 will be used towards the development of a 'Core Outcome Set' for Lichen Sclerosus (see next section for further details, including how to get involved in this work).

Future research

The Core Outcomes for ReseArch in Lichen Sclerosus (CORALS) project will establish the most important outcomes to measure in future clinical trials assessing Lichen Sclerosus.

Published randomised controlled trials of treatments for Lichen Sclerosus use different ways of measuring response to treatments (outcomes). This prevents the results of trials from being combined. If trial results were combined, we would have stronger evidence on which to base treatment making decisions.

The CORALS project aims to obtain international agreement on what aspects of the condition (also called 'domains') should be measured in clinical trials of Lichen Sclerosus.

These 'core' domains will then be used inform an international 'Core Outcome Set' for use in all future Lichen Sclerosus trials.

Want to get involved?

We are looking for people to participate in an online consensus survey towards the end of 2019. The survey will have up to three rounds which will be sent out over a 3-month period. You will be asked to vote on which domains you think are most important to include in all future clinical studies of Lichen Sclerosus. The information that you provide will be anonymised.

If you want to be considered for this project please contact CORALS@nottingham.ac.uk to express your interest.



We hope you found this newsletter interesting.

Thank you again for taking part in the Lichen Sclerosus Priority Setting Partnership