



MUCOSAL DISEASES (ORAL, ANOGENITAL), EXTERNAL EYE DISEASE

## SETTING FUTURE RESEARCH PRIORITIES FOR LICHEN SCLEROSUS

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Introduction: Lichen sclerosus (LS) is a distressing chronic, inflammatory genital skin condition affecting men, women and children. There is a decreased quality of life, long-term complications include loss of normal anatomy from scarring, and malignant transformation. Uncertainties exist about the cause, diagnosis and management of LS. This is an underfunded and under-researched area of health; future research direction needs to ensure that limited funds are spent effectively in areas that are of the greatest importance to those most directly affected by LS.

Objective: To identify research priorities about the causes, diagnosis, management and prevention of LS in men, women and children.

Materials and Methods: A Priority Setting Partnership (PSP) was conducted from June 2017-July 2018 using James Lind Alliance (JLA) methodology. A multidisciplinary steering group including 7 patient representatives, 7 health professionals, 3 researchers/administrators and an independent JLA chair, delivered the project. Research questions were elicited and then prioritised through two widely distributed, international surveys using SurveyMonkeyTM software. A face-to-face workshop, using nominal group technique with whole group and small group discussions, was employed to achieve consensus on the 'Top 10' research priorities for LS.

Results: 653 respondents (64% patients, 35% health professionals) from 28 countries entered 2580 questions into the first survey. Eligible submissions were grouped and refined, to produce a long list of 38 questions that hadn't been answered by previous research. A second, interim prioritisation survey, completed by 954 participants (66% patients, 35%





health professionals) from 14 countries, led to 23 questions being shortlisted for further discussion. A face-to-face workshop involving 14 patients and 15 health professionals reached consensus on a 'Top 10' list of shared research questions that are important to both patients and health professionals.

Conclusions: We have achieved a consensus on 10 priority areas to direct future research that will be attractive to funders.

