

Future Research Priorities for Lichen Sclerosus - Results of a James Lind Alliance Priority Setting Partnership

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For which topic were research priorities identified?

lichen sclerosis

In which location was the research priority setting conducted?

international

Why was it conducted at all?

Lichen sclerosis (LS) is a chronic, inflammatory genital skin condition affecting men, women and children. Long-term complications include loss of normal anatomy from scarring, and malignant transformation. Uncertainties exist about the cause, diagnosis and management of LS. Existing evidence on which to make recommendations about management and the prevention of malignancy is generally poor quality.

What was the objective?

to identify future research priorities about the causes, diagnosis, management and prevention of LS in men, women and children

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

June 2017 - July 2018

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: collecting research questions: via survey, participants were asked: "Please could you suggest a maximum of five questions about lichen sclerosis that you would like to know the answer to. Your questions can be about the causes, diagnosis, treatment and prevention of lichen sclerosis.", 2580 submitted questions, additionally literature reviewed. Step 3: data processing: out-of-scope and illegible/unintelligible or too ill-defined questions removed, resulting in 38 unique uncertainties. Step 4: interim ranking: via survey, participants were asked to select their 10 most important questions, resulting in shortlist of 23 questions. Step 5: final prioritization: workshop: small group discussions with nominal group technique and small group rankings, plenary session

Which stakeholders took part?

People with lichen sclerosis, parents of children with lichen sclerosis and health professionals. Survey: 653 participants: 64% patients and 35% health professionals (29% gynaecologists, 26% dermatologists, 16% sexual health physicians, 10% general practitioners, 9% urologists). Interim ranking: 954 participants. Workshop: 14 patients and 15 health professionals.

How were stakeholders recruited?

The survey was promoted by partner organizations and social media.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 7 patient representatives (5 patients, 1 parent of a child with LS, 1 patient support organization representative), 7 health professionals (5 dermatologists, 1 gynecologist, 1 nurse), and 3 researchers/administrators.