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Core Outcomes for Research in Lichen Sclerosus

Quality of Life Domain

Working group progress:

The Quality of Life (QoL) working group have begun their research by conducting a scoping review of the literature to understand how people with lichen sclerosus have previously described the impact of their condition on their daily life. This includes its impact on their activities of daily living and lifestyles, on their relationships, and on their emotional and psychological wellbeing.

Future activities will include primary research conducted directly with patients to further our understanding and identify the key concepts important for measurement in treatment evaluation studies, and subsequently the selection or development of one or more outcome measures to appropriately assess these experiences.



Dr Rosalind Simpson
Clinical representative

Rosalind works as a consultant dermatologist in Nottingham, U.K. and Associate Professor at the University of Nottingham. She is overall lead for the CORALS project. She studied at the University of Nottingham Medical School, U.K and completed a BMedSci degree in 2002 and BMBS degree in 2004. In 2008, Rosalind commenced Dermatology specialist training. She took time out of her training program to pursue a career in Academic Dermatology and completed a program of clinical research into vulvovaginal erosive lichen planus funded through the NIHR Doctoral Research Fellowship scheme. She has a research interest in trial methodology, especially for vulval skin disorders and rare conditions; diagnostic criteria development and selecting suitable outcome measures for clinical trials and clinical practice. Rosalind was lead for the Lichen Sclerosus Priority Setting Partnership (completed in 2018). She now leads the SHELLS (Establishing Effective Diagnostic Criteria for Lichen Sclerosus) and PEARLS (Proactive Against Reactive Treatment for Lichen Sclerosus) studies. Rosalind became a Fellow of the International Society for the Study of Vulvovaginal Disease ISSVD in 2011. She is Research Lead for the British Society for the Study of Vulval Disease.



Prof Kim Thomas
Researcher

Kim is Co-Director of the Centre of Evidence Based Dermatology and Professor of Applied Dermatology Research. Her main research interests focus on conducting large, pragmatic randomised controlled trials to provide a better evidence-base for the prevention and treatment of skin disease.

In addition to the COS GLS initiative, she is an Executive Group member for the Harmonizing Outcome Measures for Eczema (HOME) initiative (www.homeforeczema.org), and is lead for the HOME Long-term Control Working Group. She also provides methodological support to other core outcome groups through the Cochrane Skin Core Outcomes Set Initiative (www.cs-cousin.org) and has helped to develop and validate a number of new outcome measurement instruments.

She has long been a supporter of patient and public involvement in research and has helped to run several skin-related Priority Setting Partnerships over the last 10 years.



Natalie VJ Aldhouse, MSc
Researcher

Natalie is a PhD candidate at the University of Nottingham and lead consultant in the Clinical Outcomes Assessment team at Clarivate (a healthcare research consultancy). Natalie's research interests focus on the integration of the patient voice into clinical research, primarily via the development or selection of patient-reported outcome measures for use in clinical trials exploring the efficacy of new treatments. Natalie has expertise in both primary and secondary qualitative research methods and has previously explored the quality of life of patients with a wide variety of conditions, including alopecia areata, endometriosis, kidney disease, and hepatitis B.
