

# Lymphedema Research Prioritization Partnership: A Collaborative Approach to Setting Research Priorities for Lymphedema Management

Underwood et al. (2019)  
<https://doi.org/10.1089/lrb.2018.0026>

## **For which topic were research priorities identified?**

lymphedema

## **In which location was the research priority setting conducted?**

Europe - United Kingdom

## **Why was it conducted at all?**

More research is needed in lymphedema management to strengthen the evidence base and ensure patients receive clinically and cost-effective treatment. It is critical that patients and clinicians are involved in prioritizing research to ensure that it reflects their needs and is not biased by commercial interests.

## **What was the objective?**

to set the research priorities for lymphedema management in the United Kingdom, through collaboration with patients, carers, and clinicians

## **What was the outcome?**

a ranking list of 10 research questions

## **How long did the research prioritization take?**

No information provided.

## **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: generation of research questions, survey asking: What questions about the treatment of Lymphedema do you feel need to be answered by research? What questions about lymphedema treatment have you and your healthcare professional been unable to answer?, 631 submission. Step 3: data processing: collation, verification and formatting, out-of-scope questions removed, literature review to verify submissions, additional unanswered questions were added from literature review, resulting in 126 broad research questions. Step 4: 4 rounds of Delphi survey: Delphi round 1: participants were asked to rate importance of questions, rounds 2 to 4: participants were asked to rank questions

## **Which stakeholders took part?**

Patients, carers, clinicians. Survey: 213 participants: 108 patients, 10 carers, 92 clinicians, 7 academics/researchers, 5 support groups. Delphi round 1: 51 participants. Delphi round 2: 47 participants. Delphi round 3: 50 participants. Delphi round 4: 50 participants.

## **How were stakeholders recruited?**

The survey was presented at both the LSN and BLS conferences and advertised via their newsletters, website, and social media forums. In addition, individuals with lymphedema and clinicians were asked to publicize to their local support groups, and the Children's Lymphoedema Special Interest Group promoted the research during its Lymphaletics event for children and young people with lymphedema and their carers. A purposive, representative sample of patients, carers, and clinicians, who volunteered in phase one, participated in phase 3.

## **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 members were involved in data processing.