

# ILF-COM Reporting From the United Kingdom

Dr Melanie Thomas, ILF Director, National Clinical Lead for Lymphoedema in Wales, UK

## Introduction

The ILF recognised that there was a lack of clarity surrounding outcome measures for people with lymphoedema. Uncertainty on outcome measures can be directly linked to the lack of investment to establish lymphoedema services and the reimbursement of care.

The ILF-COM is an international, multi-sponsored project to investigate outcome measures used in lymphoedema. The project included a scoping systematic review, a qualitative study to explore reimbursement issues faced by the medical device industry and an international survey.

This survey received 8,014 replies from 60 countries across the World. One of which was the United Kingdom.

## Aim

To explore the importance of lymphoedema outcome measures from patients and health care professionals within the United Kingdom.

## Method

The ILF-COM survey was devised from meetings with patients, professionals and the medical device industry in Copenhagen, Denmark in May 2018. International lymphoedema experts also reviewed the content and format. The survey was piloted in October 2018 by the Danish Lymphoedema Framework and some questions were re-written for clarity.

The survey was translated into English, French, German, Italian, Japanese, Turkish and Dutch and was uploaded onto Survey Monkey. The survey was open for 4.5 months, closing on March 31st 2019.

In the UK, all lymphoedema professional and education groups were contacted via email and asked to disseminate the ILF-COM link to colleagues creating a snowball effect. The British Lymphology Society and lymphoedema education establishments also emailed the link to their membership.

The UK Social Media campaign commenced in December 2018 raising the awareness amongst patient support and professional groups utilising Twitter and Facebook.

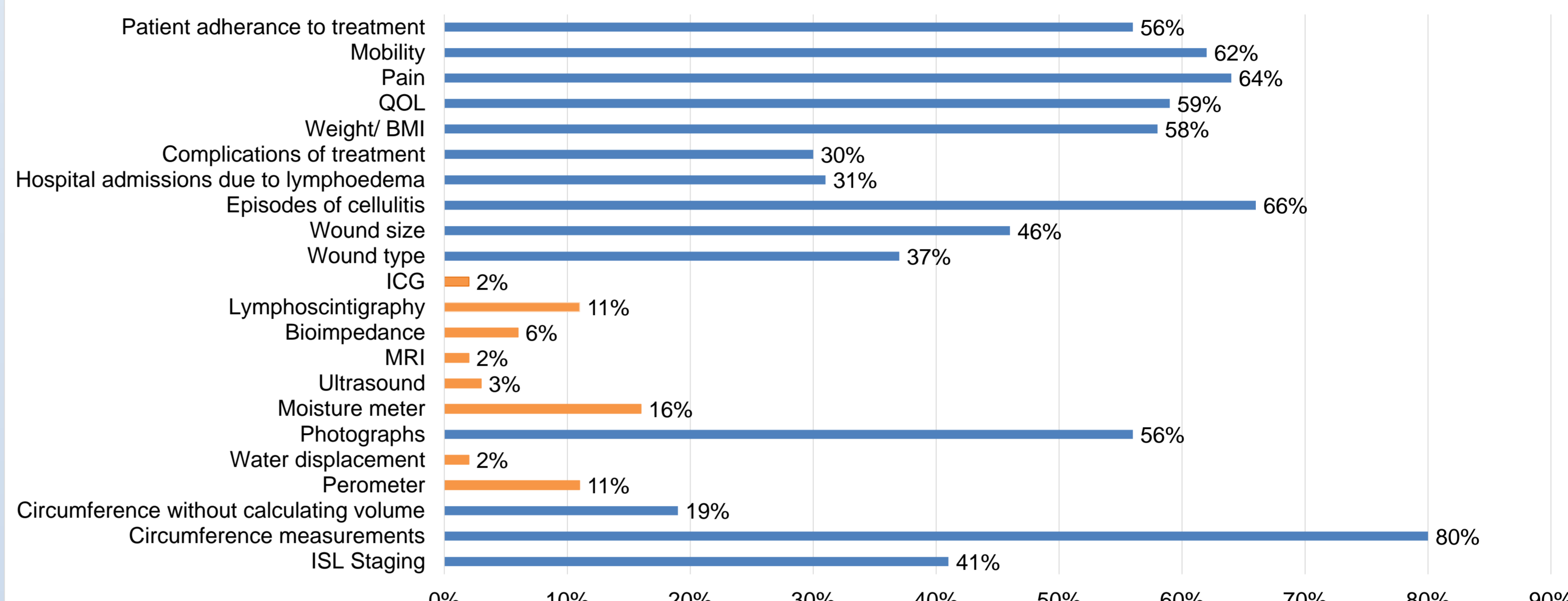
Ethical approval for ILF-COM was not required as no identifiable data has been collected.

## Results

944 participants responded to the survey. 56% (520) Patients; 37% (351) Professionals and 7% (73) Others (including medical device industry). Of the Professionals 2% Medical Doctors; 61% Nurses; 15% Physiotherapists; 3% Occupational Therapists and 19% Other. 78% work in the public setting and 26% private. Of the professionals 29% work in the community; 27% Hospitals; 30% Lymphoedema Clinic; 4% Wound Clinic; Academic 3%; Other 3%.

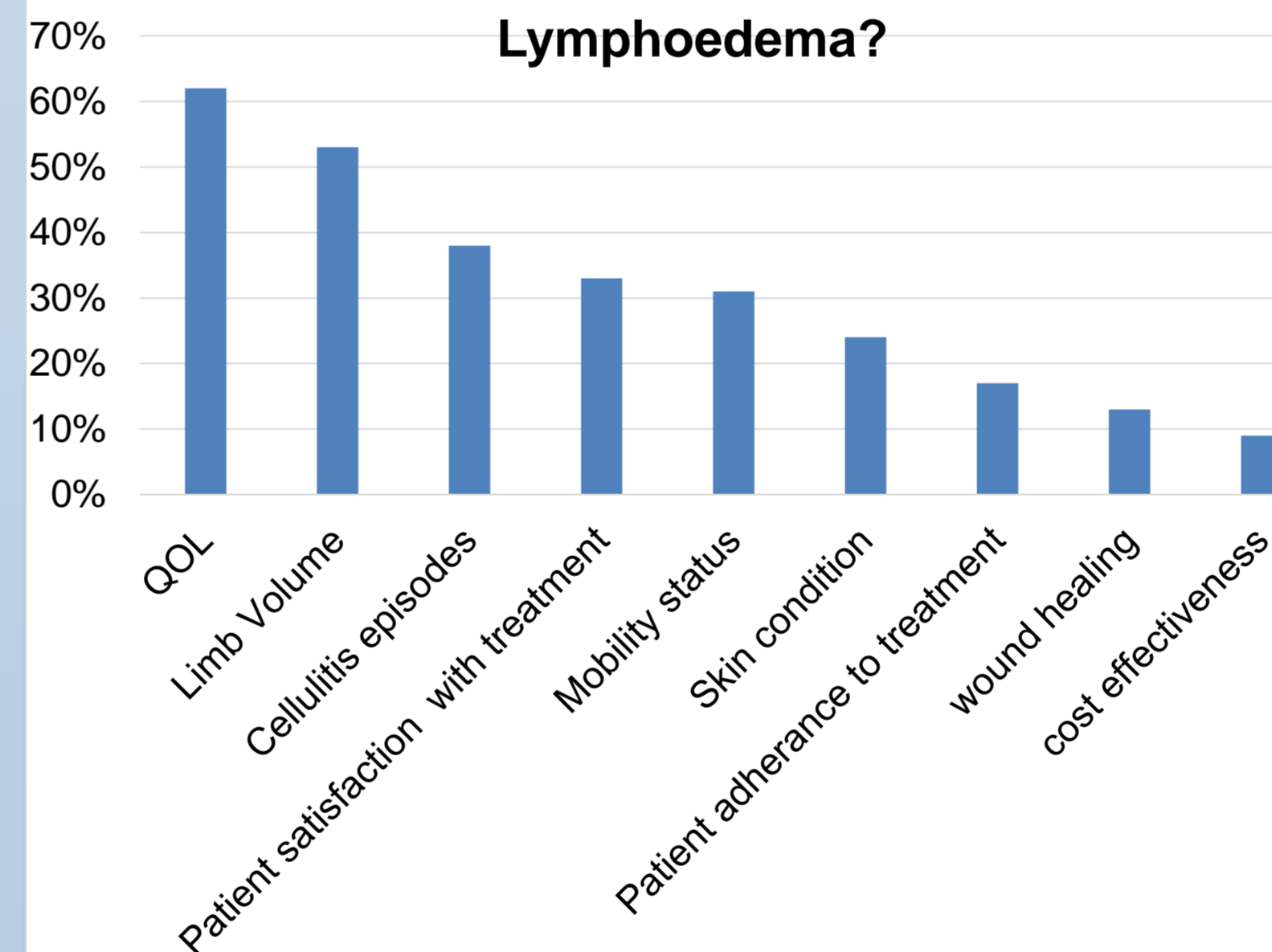
Many different outcomes are captured in practice. As seen below eight different electrical modalities/machines are used. The most common outcome measure captured is Circumference Measurements, Episodes of Cellulitis and Pain.

### What is Used in Clinical Lymphoedema Practice to Determine Outcome?

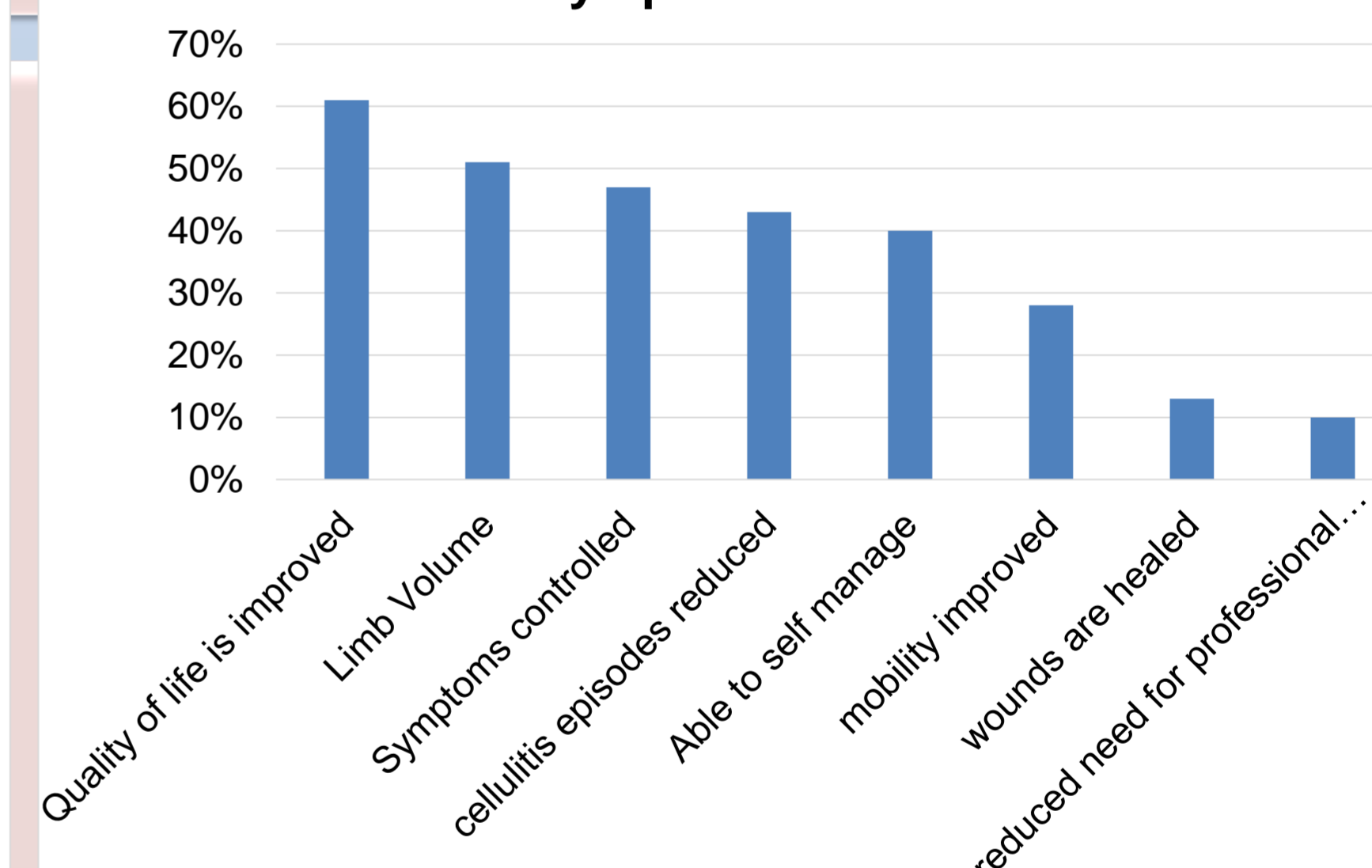


All participants in the UK reported that Quality of Life (QOL) was the most important outcome measure followed by Limb Volume and Cellulitis Episodes. Similarly, the participants reported that a successful outcome to measure lymphoedema treatment was an improvement in QOL, reduction in Limb Volume and Symptoms such as pain/ heaviness were controlled.

### What are the Most Important Outcome Measures in Chronic Oedema/ Lymphoedema?

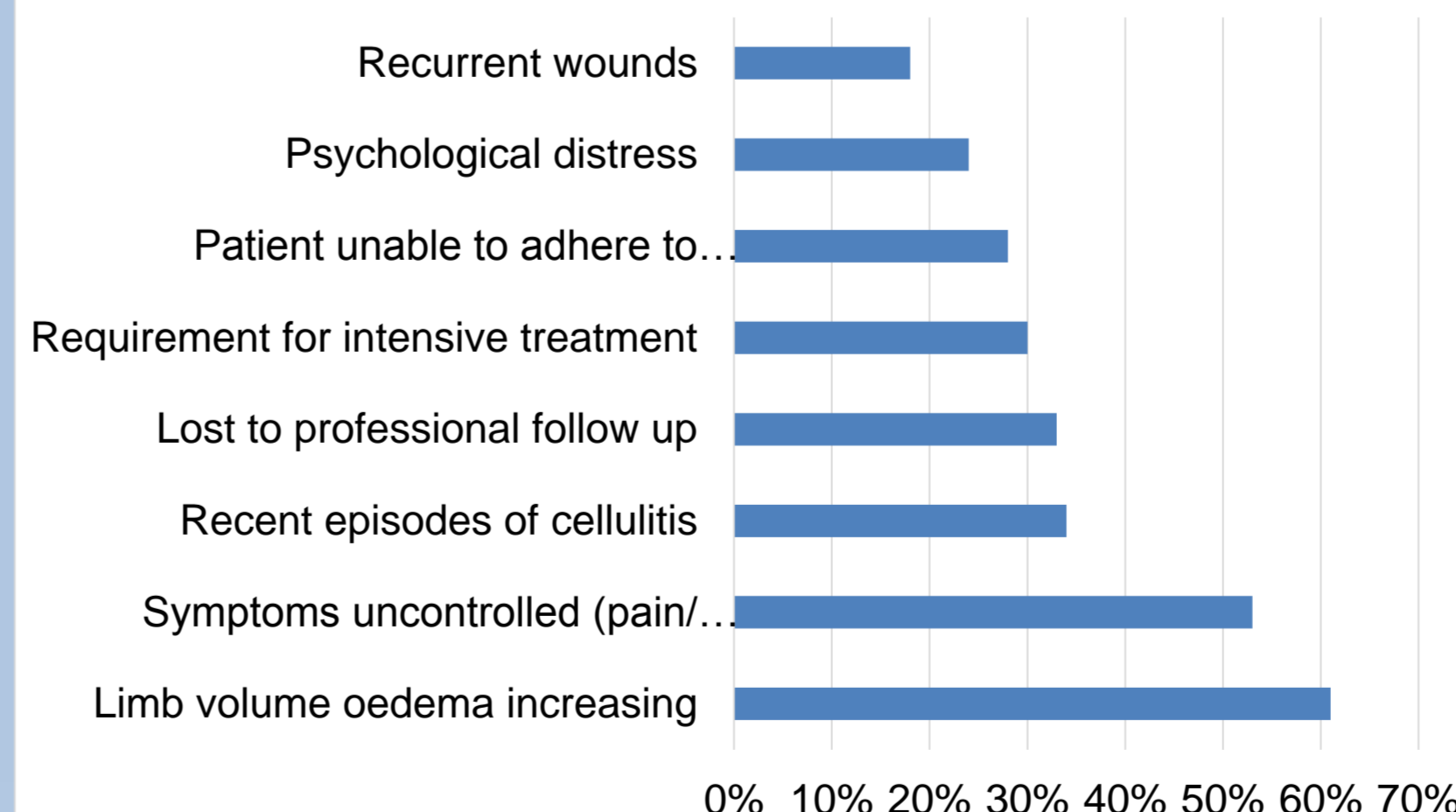


### What is the most Successful Outcome Measure for Chronic Oedema / Lymphoedema?

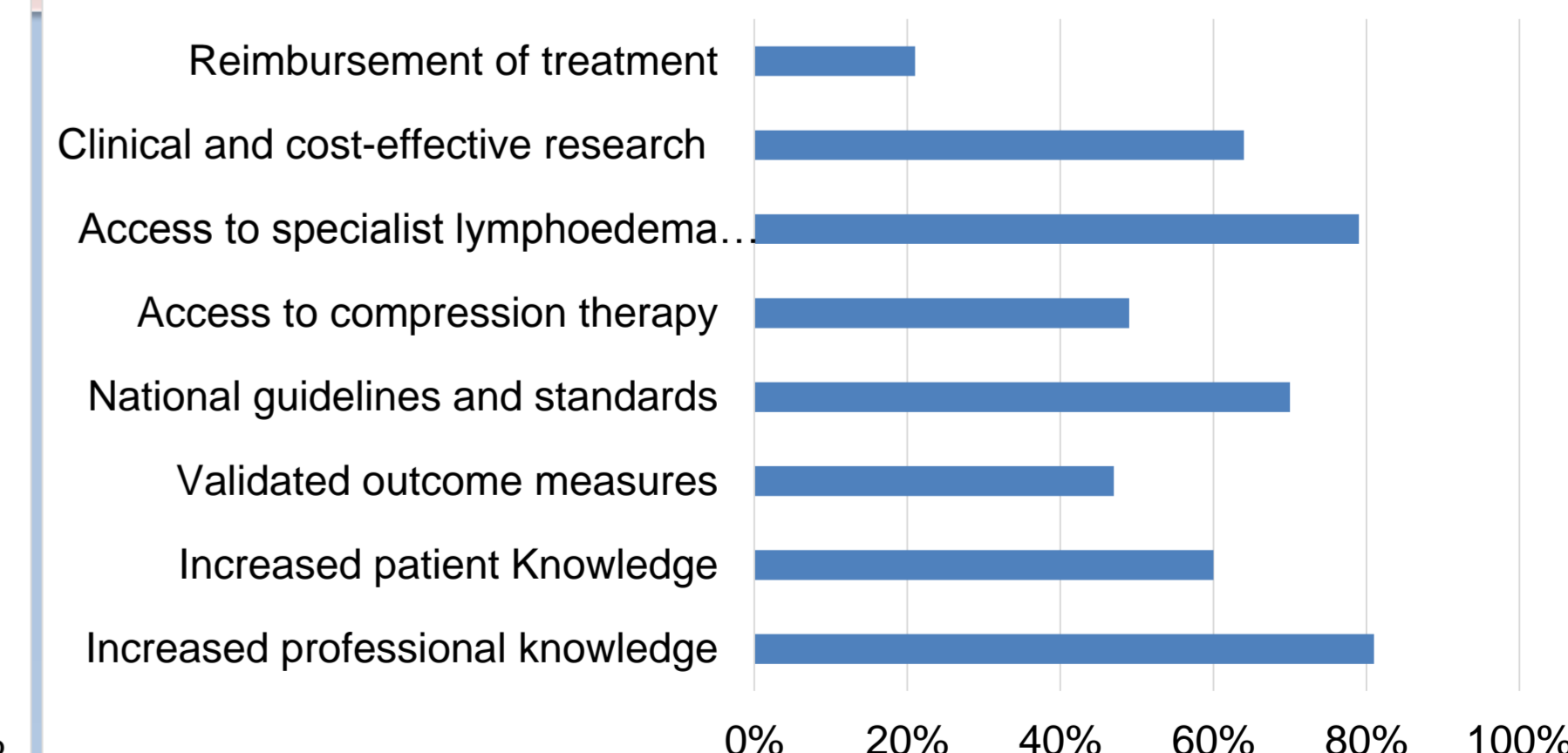


Similarly, factors that indicate that treatment is failing are Limb Volume increasing and Symptoms uncontrolled (Pain and Heaviness). Only 36% of the participants felt that outcome of treatment for lymphoedema was measured. The largest factor which could improve adoption of lymphoedema outcome measures was increased professional knowledge and increased access to lymphoedema services.

### What Factors Indicate Treatment is Failing?



### What Factors Could Improve Adoption of Chronic Oedema/Lymphoedema Outcome Measures?



## Conclusion

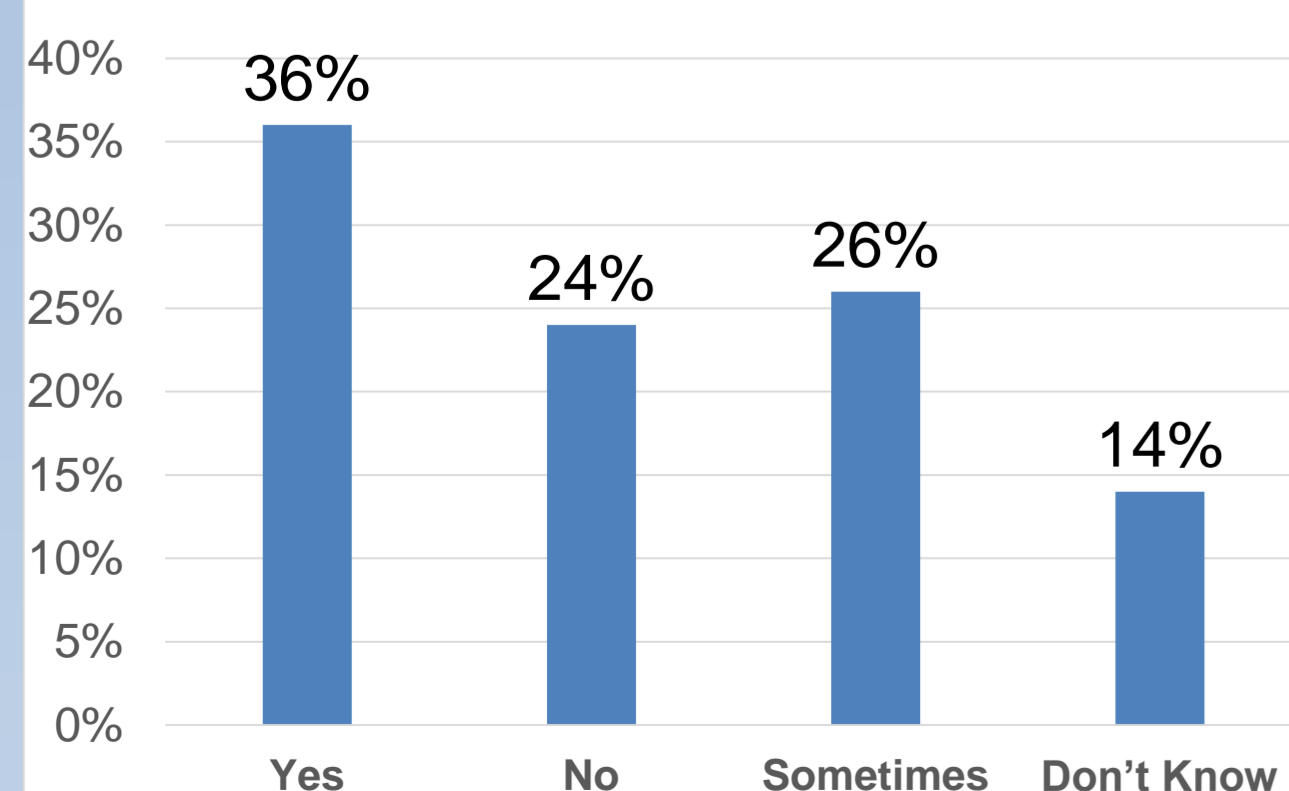
The results indicate that QOL, Volume Measurements and Symptoms ( Pain and Heaviness) are vitally important outcome measures. However, it is unknown if these outcomes are regularly captured in clinical practice on assessment and/or follow up appointment.

The results from this survey will be used to develop a strategic approach to outcome measure by the ILF over the next years.

## Acknowledgements

Special thanks to all the Lymphoedema Support Groups across the UK for raising the profile of the survey on social media. Thanks also to the lymphoedema professional groups including NLP, BLS, MLD UK, Lipoedema UK and manufacturers for disseminating amongst colleagues.

### In your experience is chronic oedema/ lymphoedema outcome of treatment measured?



### What Treatment Do Patients Have to Pay For?

