ILF-COM
International Lymphoedema Framework — Chronic Oedema Outcome Measure

ILF-COM: Global Results

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INTERNATIONAL LYMPHOEDEMA FRAMEWORK
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Why is the ILF interested in outcomes?

Aim of ILF-COM

The ILF-COM is an international, multi-sponsored project that aims to address the lack of clarity about outcome measures for people with lymphoedema and related disorders.

The strategy included a scoping systematic review, a qualitative study to explore reimbursement issues faced by the medical device industry, and an international survey.

Current dilemmas

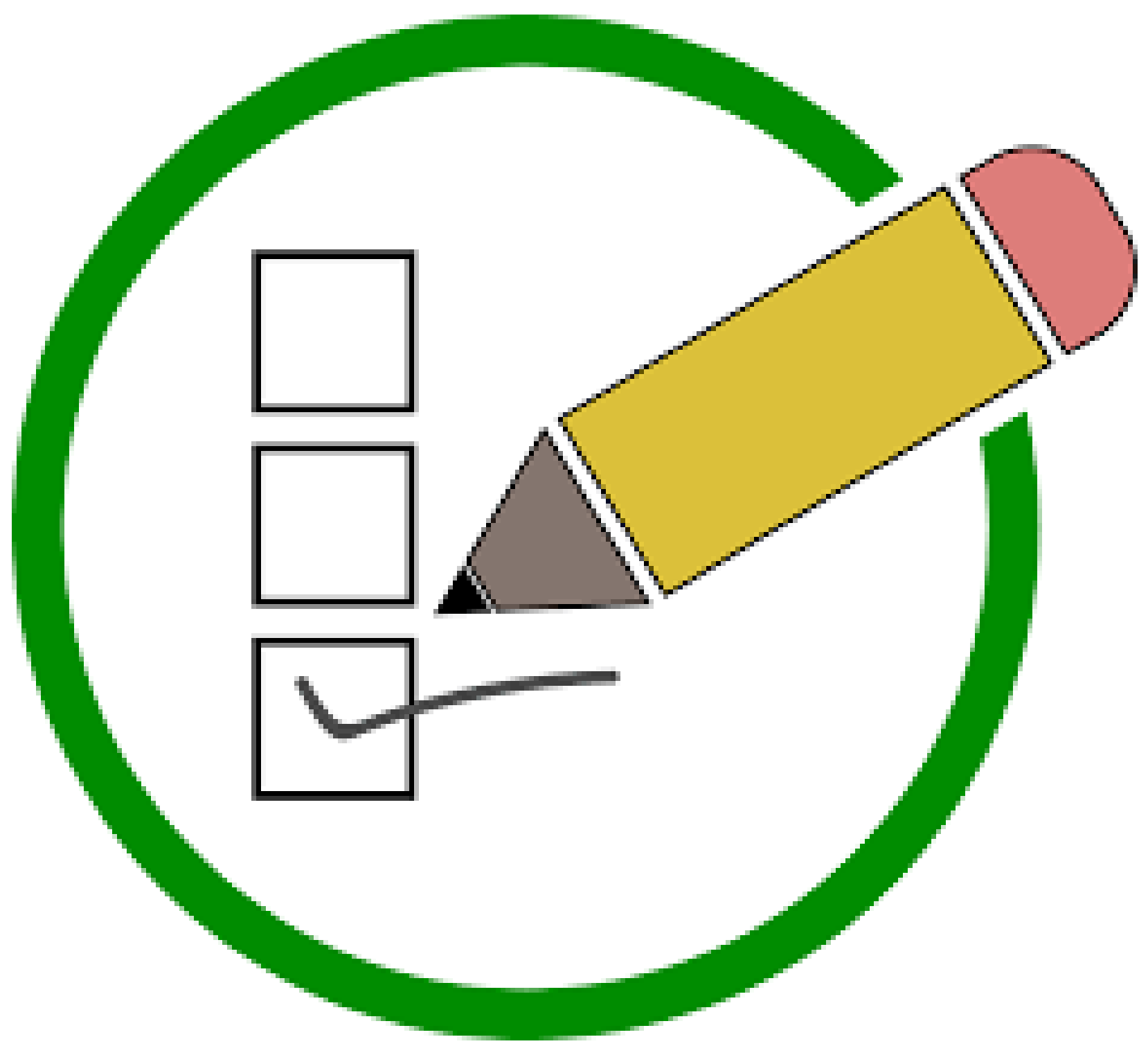
- ❖ No international standards
- ❖ Lack of definitions
- ❖ Confusion over complex decongestive therapy (CDT)

Lack of outcome measures leads to:

- ❖ Reason for lack of services
- ❖ Inability to benchmark care between services
- ❖ Inability to identify patient versus professional priorities of outcomes

➡ LIMPRINT showed size and impact of chronic oedema in health services internationally

➡ Urgent need to **define**, **develop** and **validate** standardised international outcomes



Number of respondents = 8,014

Funding corsortium

❖3M	❖Thuasne
❖Essity (BSN)	❖Specialbandager
❖Tactile	❖Sigvaris

Process of development of methods

1. Stakeholder meeting with professionals involved in lymphoedema management, patients and the **medical device industry**
2. Pilot questionnaire completed in Denmark
3. The questionnaire was translated into: English, French, German, Italian, Japanese, Turkish and Dutch
4. All questionnaires were uploaded on to SurveyMonkey

Survey dissemination strategy

➡ **DISSEMINATION THROUGH FRAMEWORKS**

1. Australia
2. Belgium
3. Canada
4. Denmark
5. France
6. Ireland
7. Italy
8. Japan
9. Netherlands
10. New Zealand
11. South Africa
12. Switzerland
13. Turkey
14. UK
15. USA
16. Other

➡ **SOCIAL MEDIA CAMPAIGN**

Main outcomes

Respondents (n=8,014) from 61 countries were asked to complete a survey containing 14 questions. Some questions that were not suitable to be completed by patients were hidden.

1. Both patients (fig 1) and professionals (fig 2) indicated that limb volume, quality of life status and mobility status are the most important outcomes in chronic oedema/ lymphoedema that should be measured.

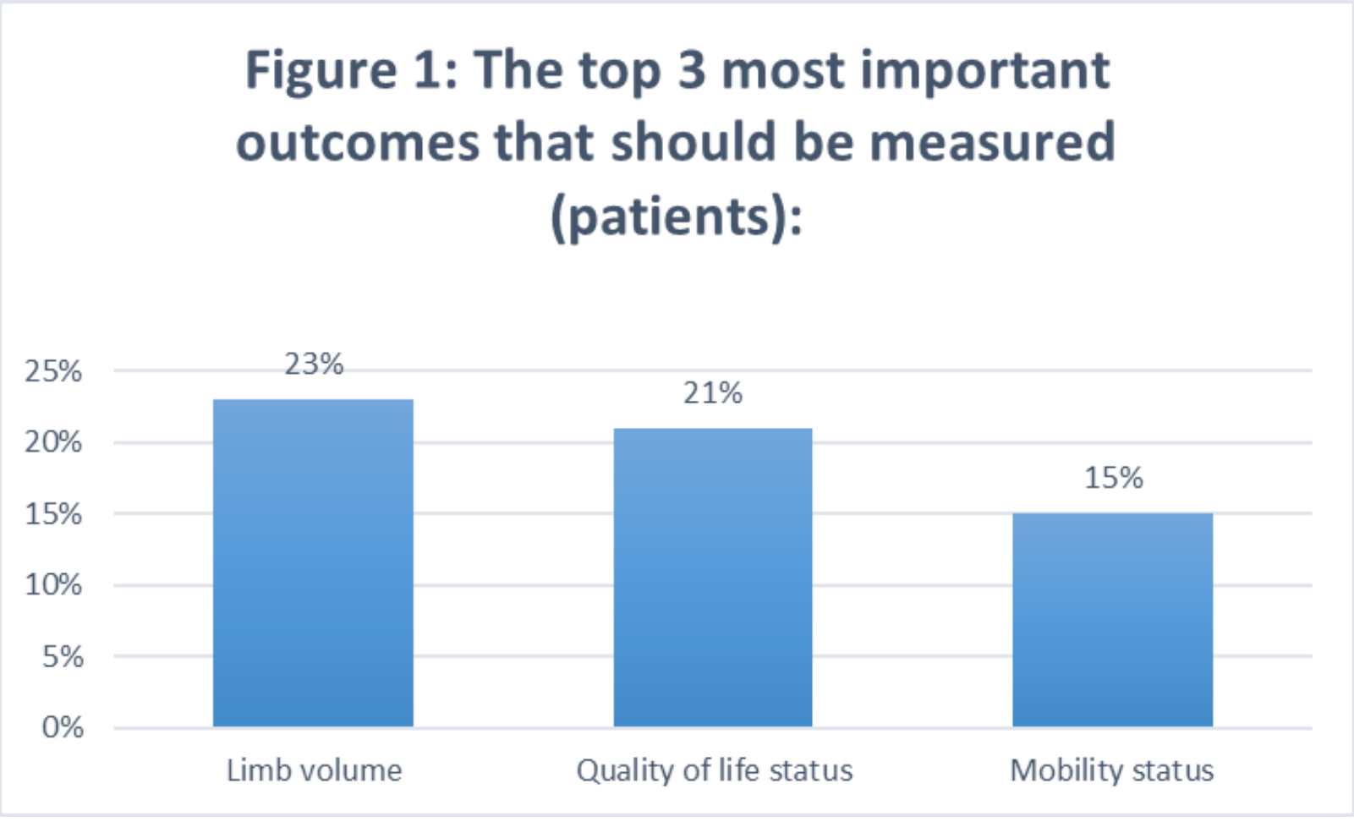


Figure 1: The top 3 most important outcomes that should be measured (patients):

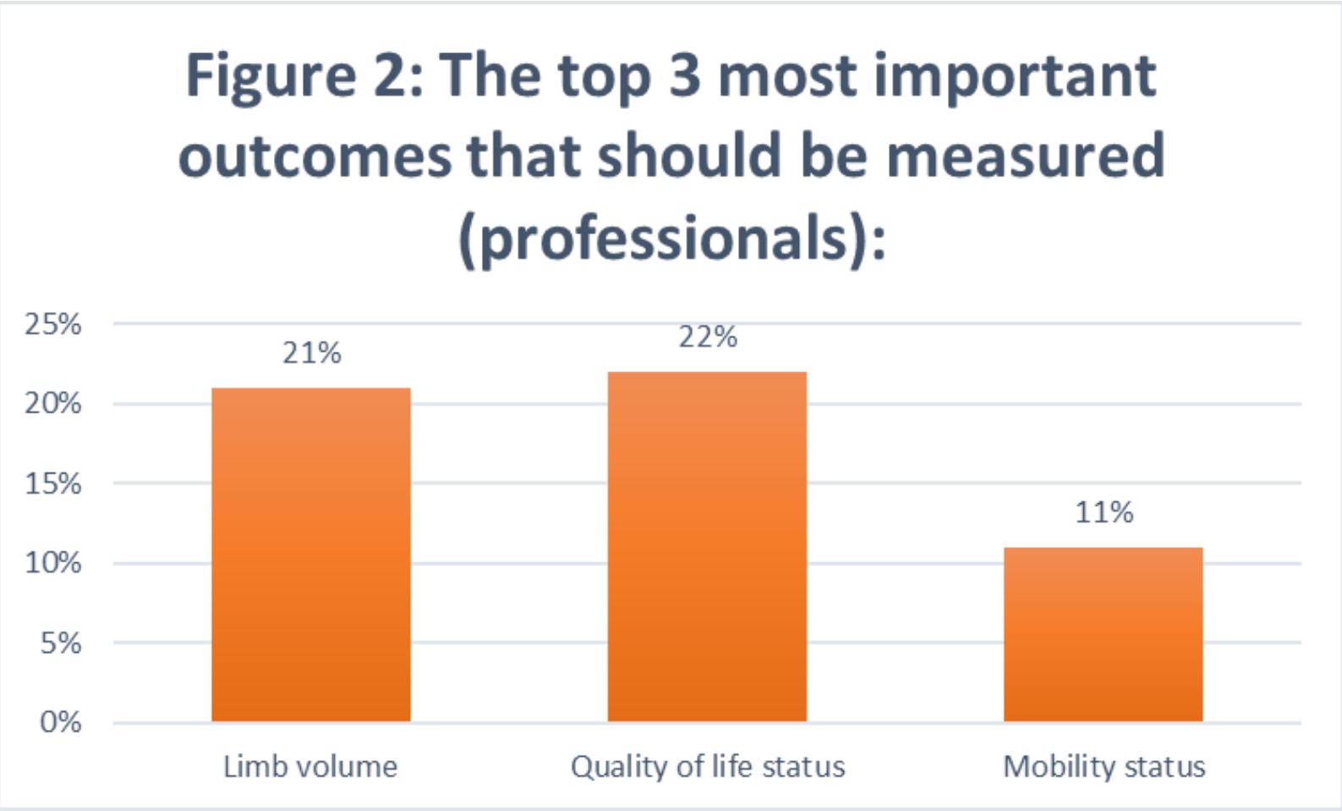


Figure 2: The top 3 most important outcomes that should be measured (professionals):

2. Both patients (fig 3) and professionals (fig 4) indicated that the top 2 successful outcomes for chronic oedema/ lymphoedema are: limb volume or oedema stable and quality of life is improved. The top 3 most successful outcome differed: symptoms are controlled (patients) and ability to self-manage with professional support (professionals).

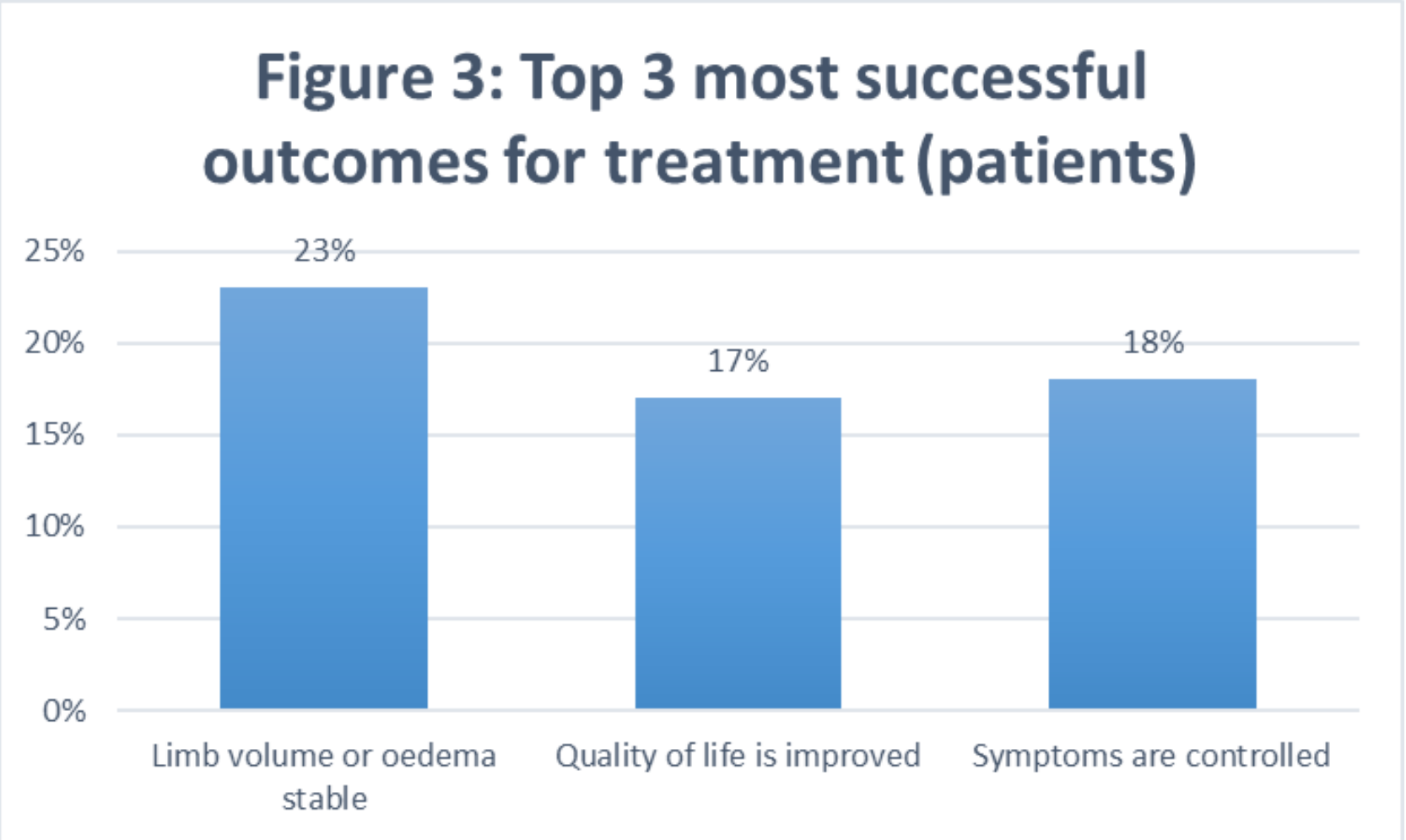


Figure 3: Top 3 most successful outcomes for treatment (patients)

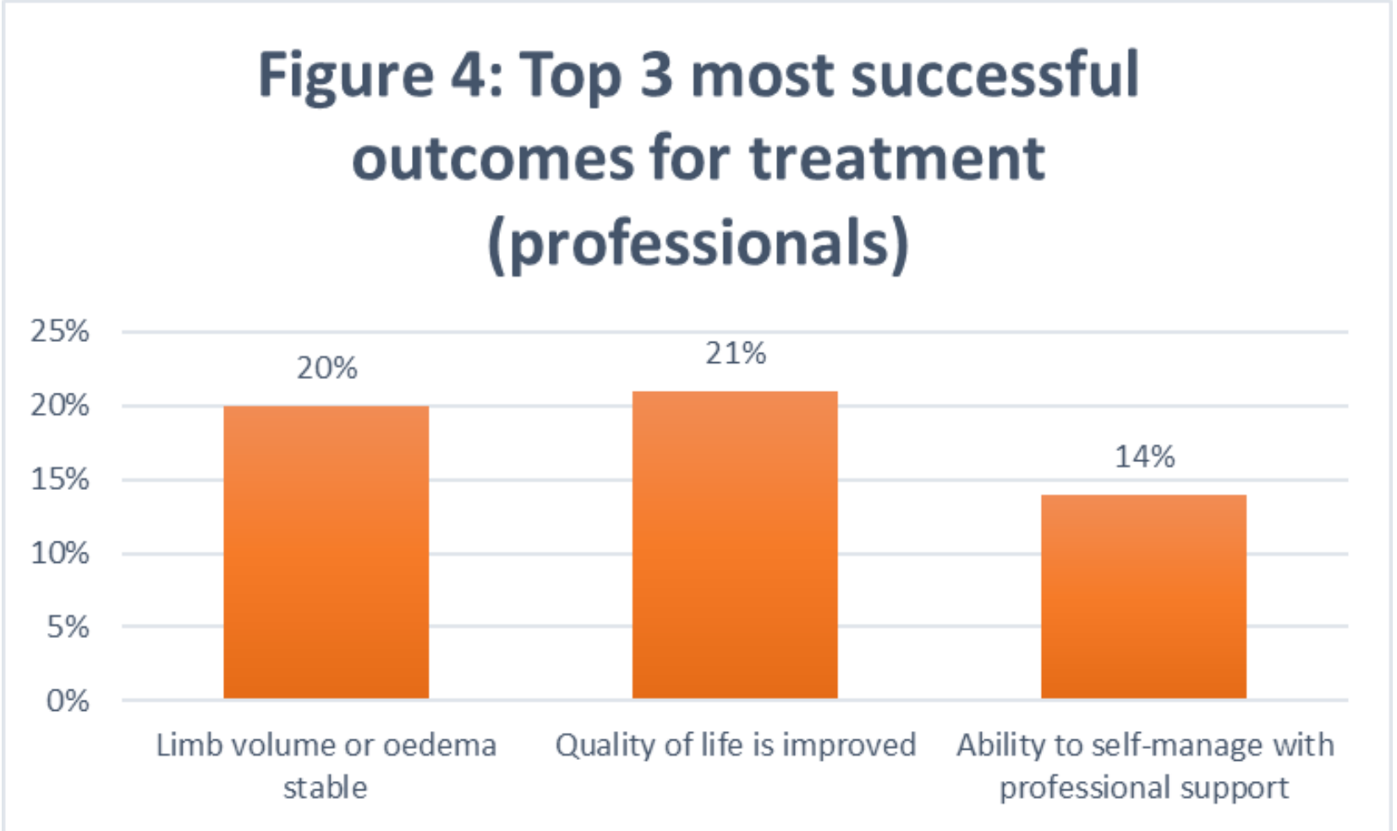


Figure 4: Top 3 most successful outcomes for treatment (professionals)

3. Limb volume or oedema increased was perceived as the factor indicating ineffective or failing treatment in both groups. Patients (fig 5) perceived uncontrolled symptoms and loss of professional follow-up as other indicative factors, whereas professionals (fig 6) selected patients unable to adhere to treatment and symptoms uncontrolled as indicative.

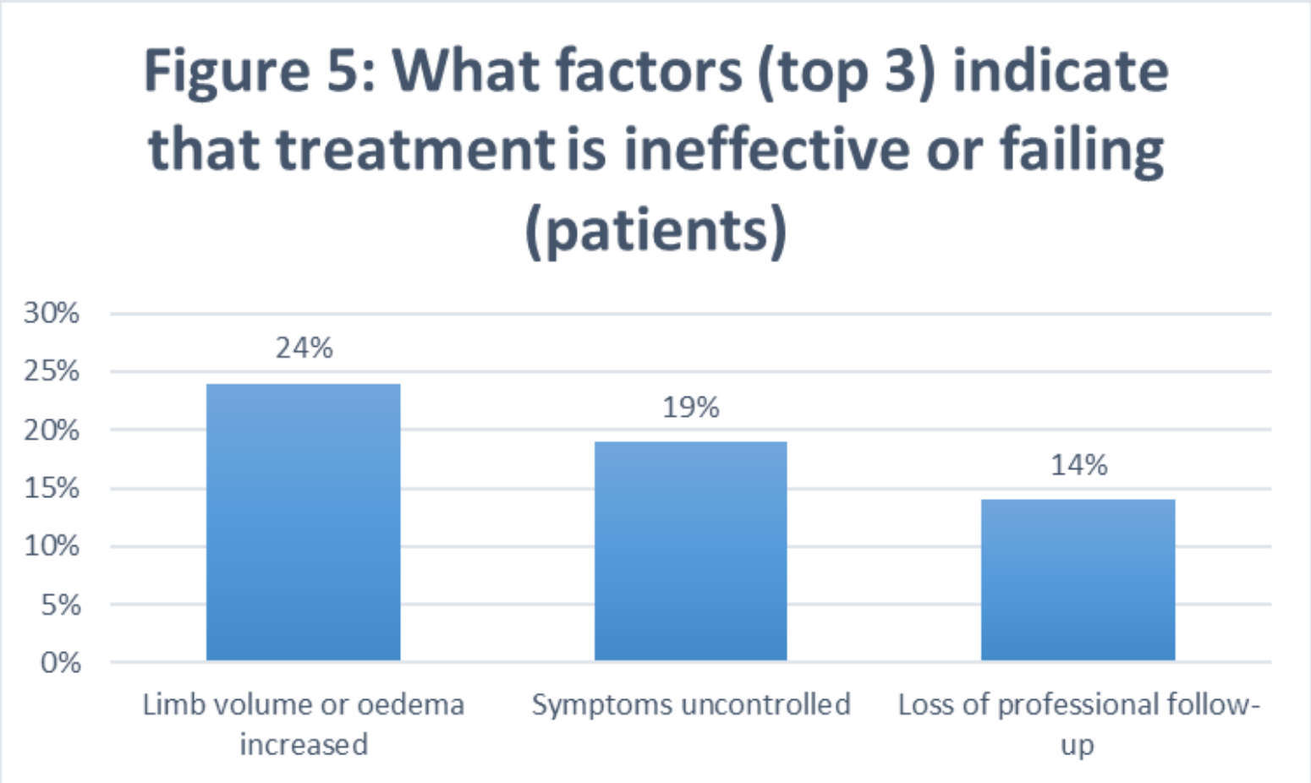


Figure 5: What factors (top 3) indicate that treatment is ineffective or failing (patients)

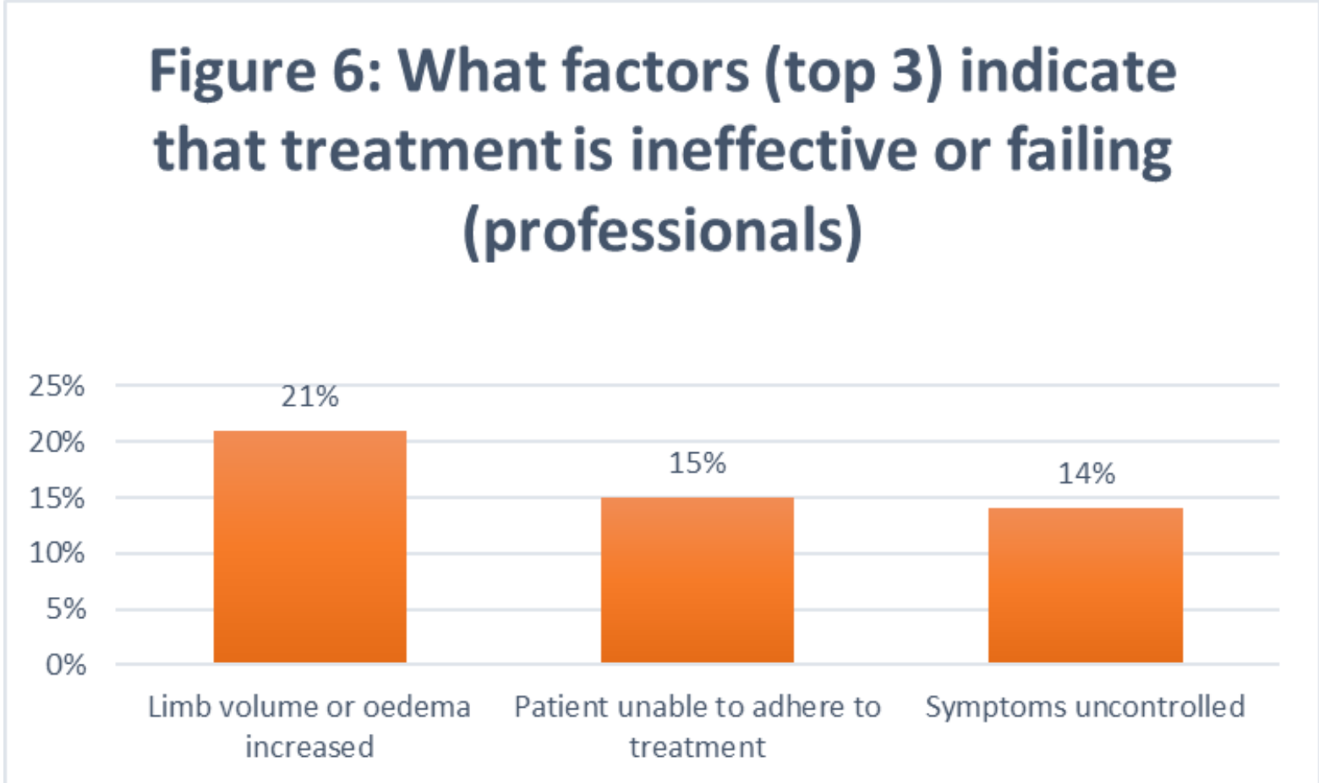


Figure 6: What factors (top 3) indicate that treatment is ineffective or failing (professionals)

4. The most important factor that could improve the adoption of chronic oedema/ lymphoedema measures was increased professional knowledge for both patients (fig 7) and professionals (fig 8). Patients selected access to specialist chronic oedema/ lymphoedema services and reimbursement of treatment as other important factors, whereas professionals perceived increased patient knowledge and national guidelines and standards as important.

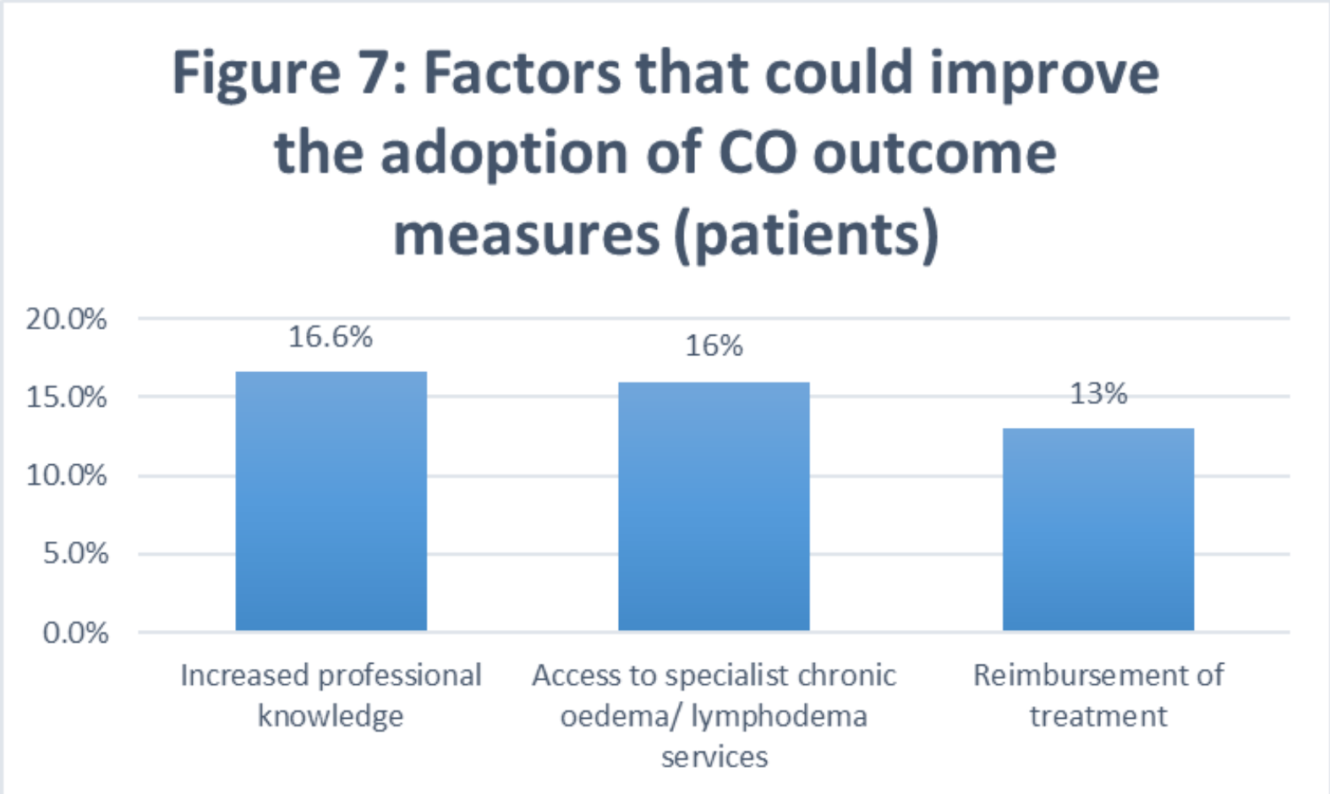


Figure 7: Factors that could improve the adoption of CO outcome measures (patients)

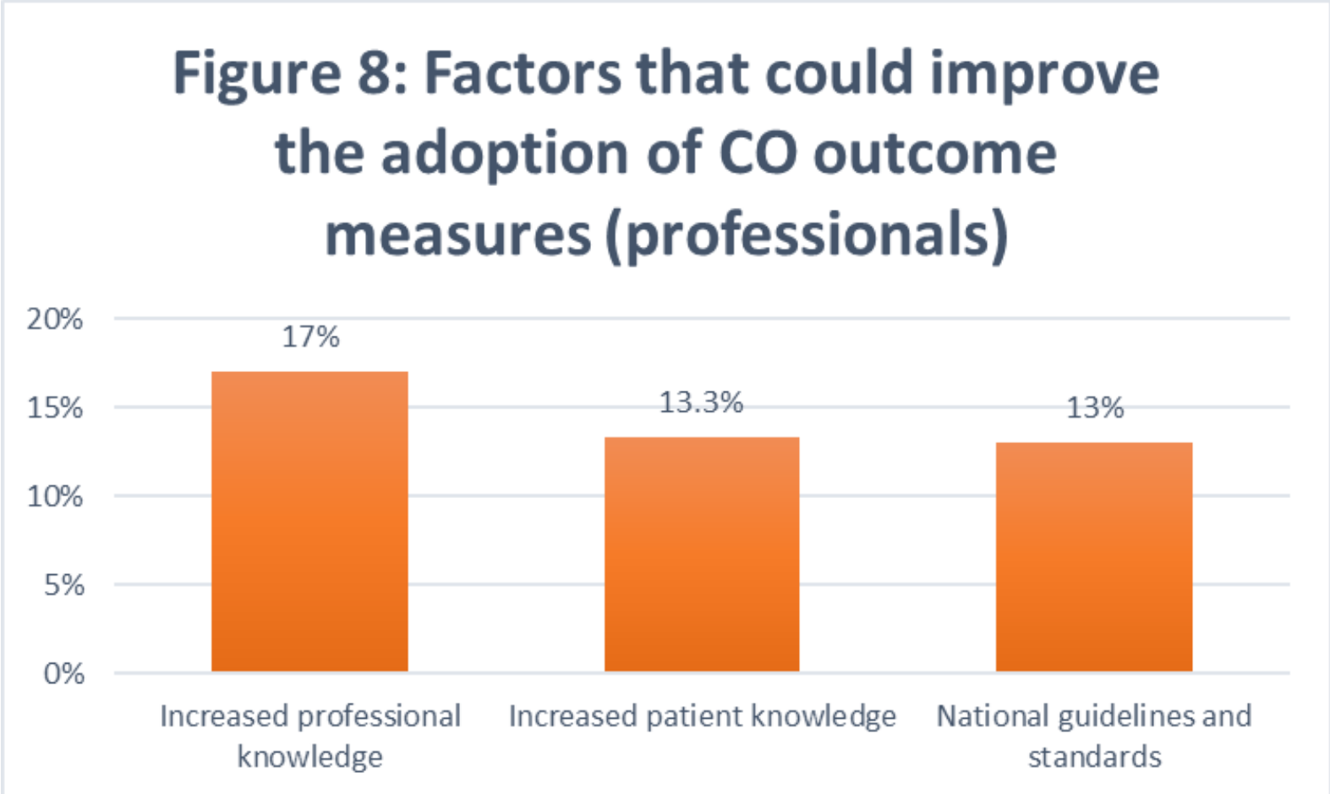


Figure 8: Factors that could improve the adoption of CO outcome measures (professionals)

Recommendations for development

Findings from the ILF-COM survey will be discussed at the 2019 ILF Conference in Chicago, USA. Results from the survey will be used to develop a strategic approach to outcome measures by the ILF over the next years.