

## ILF COM: The Power of Social Media

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### Why it matters?

To reach people who may otherwise not have a say especially patients and their families. The survey that was distributed via social media was completed by:

**67.2%** patients

**32.8%** professionals

### Who it matters to?

- ❖ **Patients**
  - ❖ All patient groups, their families and carers
- ❖ **Professionals**
  - ❖ All healthcare groups including medical device companies

### Methods & Sampling strategy

1. Pilot survey
2. Final survey on SurveyMonkey
3. Social media campaign

-  • Official Lymphie Strong Inspiration Group
- Lymphedema
- Lymph-what-oedema

-  • Official ILF account @ILF\_Lympho

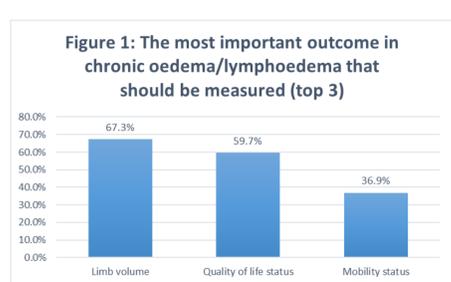
-  • Official ILF website [www.lympho.org](http://www.lympho.org)

### Results

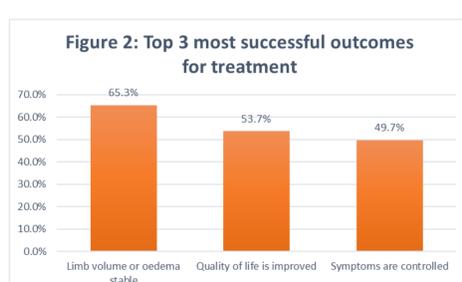
Reporting on 'Other country' option (484/8000): 47 participating countries in total:

Algeria	Angola	Argentina	Austria	Azerbaijan	Barbados	Bosnia and Hercegovina	Brazil
Bulgaria	Burkina Faso	Canary Islands	Chile	Costa Rica	Croatia	Cyprus	Dominican Republic
Egypt	Faroe Islands	Finland	Germany	Ghana	Greece	Honduras	India
Indonesia	Israel	Kenya	Lebanon	Luxembourg	Malaysia	Martinique	Montenegro
Morocco	Norway	Poland	Portugal	Qatar	Romania	Russia	Saudi Arabia
Singapore	Slovakia	Slovenia	Spain	Sweden	Tunisia		

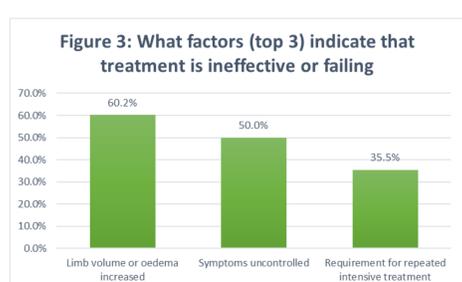
**1.** Respondents indicated that limb volume, quality of life status and mobility status are the most important outcomes in chronic oedema/lymphoedema that should be measured (fig 1).



**2.** Respondents indicated that the top 3 successful outcomes for chronic oedema/lymphoedema are (fig 2): limb volume or oedema stable, quality of life is improved, and symptoms are controlled.

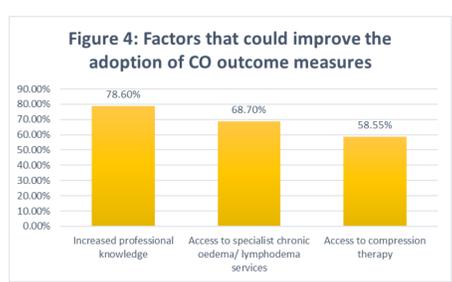


**3.** The top 3 factors indicating that treatment is ineffective or failing were perceived as (fig 3): limb volume or oedema increased, symptoms are uncontrolled, and requirement for repeated intensive treatment.



### Conclusions

**4.** How adoption of CO/lymphoedema outcome measures could be improved (fig 4)?



#### Benefits of using social media within surveys:

- A new method for the ILF
- Possible to reach hard-to-reach groups
- Speed of survey circulation
- Easy to complete using a laptop or mobile phone

The ILF-COM survey was circulated on social media in December 2018 but the greatest number of responses was in March 2019.