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

Results

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

<table>
<thead>
<tr>
<th>Country</th>
<th>Country</th>
<th>Country</th>
<th>Country</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Algeria</td>
<td>Angola</td>
<td>Argentina</td>
<td>Austria</td>
<td>Azerbaijan</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>Burkina Faso</td>
<td>Canary Islands</td>
<td>Chile</td>
<td>Costa Rica</td>
</tr>
<tr>
<td>Egypt</td>
<td>Faroe Islands</td>
<td>Finland</td>
<td>Germany</td>
<td>Ghana</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Israel</td>
<td>Kenya</td>
<td>Lebanon</td>
<td>Luxembourg</td>
</tr>
<tr>
<td>Morocco</td>
<td>Norway</td>
<td>Poland</td>
<td>Portugal</td>
<td>Qatar</td>
</tr>
<tr>
<td>Singapore</td>
<td>Slovakia</td>
<td>Slovenia</td>
<td>Spain</td>
<td>Sweden</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Reporting on ‘Other country’ option (484/8000): 47 participating countries in total:

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.

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

Conclusions

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.