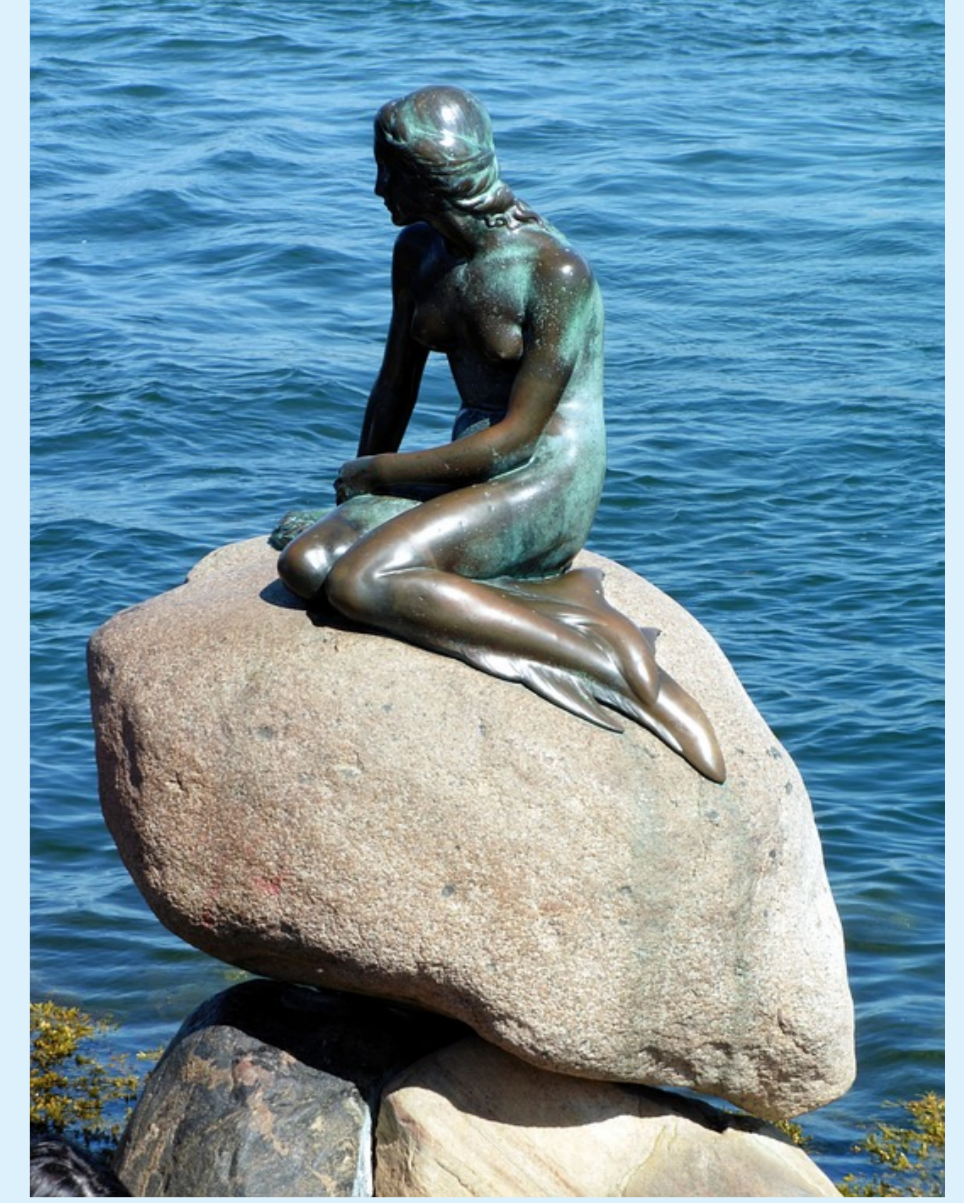
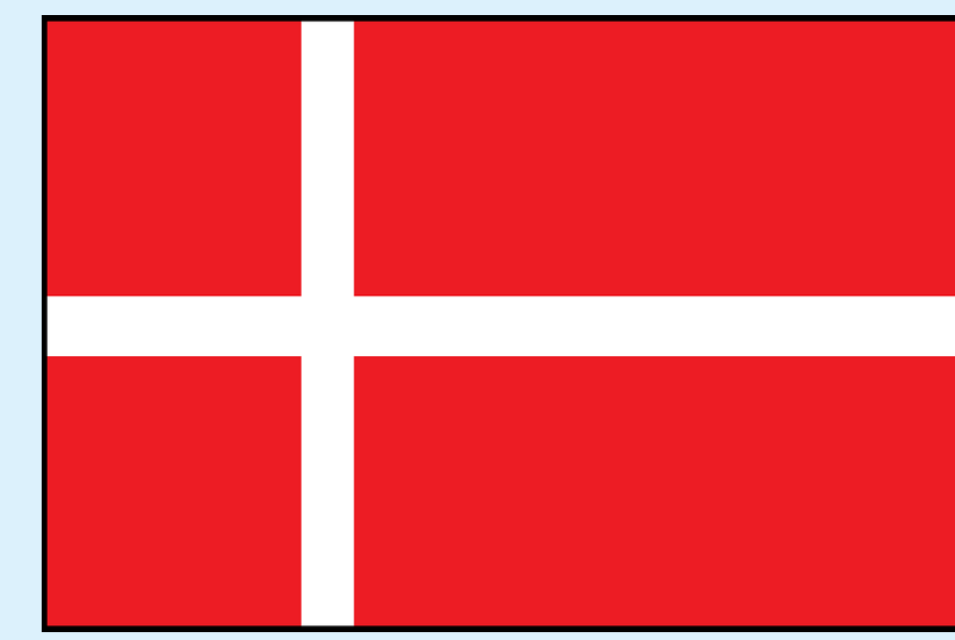


University of Copenhagen: Bispebjerg Hospital
Copenhagen Wound Healing And Lymphoedema Centre



REGION

ILF-COM: Development of the questionnaire and results from Denmark

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BACKGROUND AND AIM

- ❖ Lack of national standards for outcome measures for chronic oedema/ lymphoedema
- ❖ What to measure?
- ❖ How to measure?
- ❖ The ILF Denmark played a **key role** in the development of ILF-COM

DEVELOPMENT OF METHODS

1. INITIAL DEVELOPMENT

- ❖ Stakeholder meeting, Copenhagen
- ❖ Open space meeting to define current challenges:
 - ✓ Academics
 - ✓ Clinicians
 - ✓ Patients
 - ✓ Medical device industry
- ❖ Create initial questions
- ❖ Design the process of implementation

2. 2018 ILF CONFERENCE IN ROTTERDAM, NETHERLANDS

- Stakeholder meetings:
- ❖ National Framework Leads
 - ❖ Industry partners
 - ❖ Key clinical and methodology experts

The aim was to look at the face validity of the original questionnaire:

- ❖ Draft 2 Questionnaire produced
- ❖ International consensus on methods

3. PILOTING

Denmark:

- ❖ Pilot (paper-based questionnaire)
- ❖ Danish Lymphoedema Framework
- ❖ Danish Wound Healing Society
- ❖ Recorded interviews with industry members

4. TRANSLATIONS

Translation and back translation into:

- ❖ Danish
- ❖ Dutch
- ❖ English
- ❖ French
- ❖ German
- ❖ Italian
- ❖ Japanese
- ❖ Turkish

Survey Monkey:

- ❖ Decision about survey tools
- ❖ Uploading translated questionnaires

5. FINAL DRAFT

- ❖ Review of questions
- ❖ Change of questionnaire to Draft 3

SUPPORT OF IMPLEMENTATION

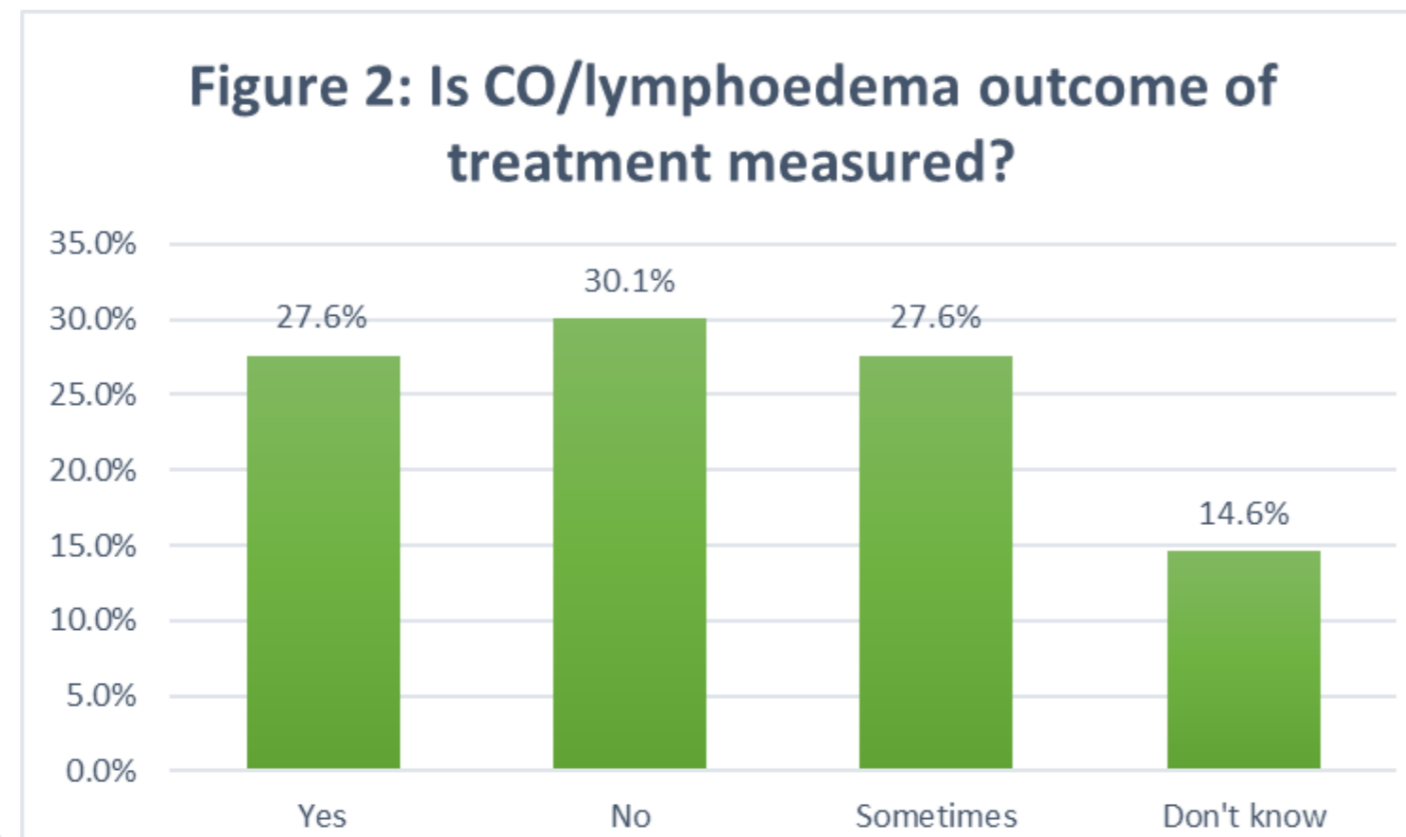
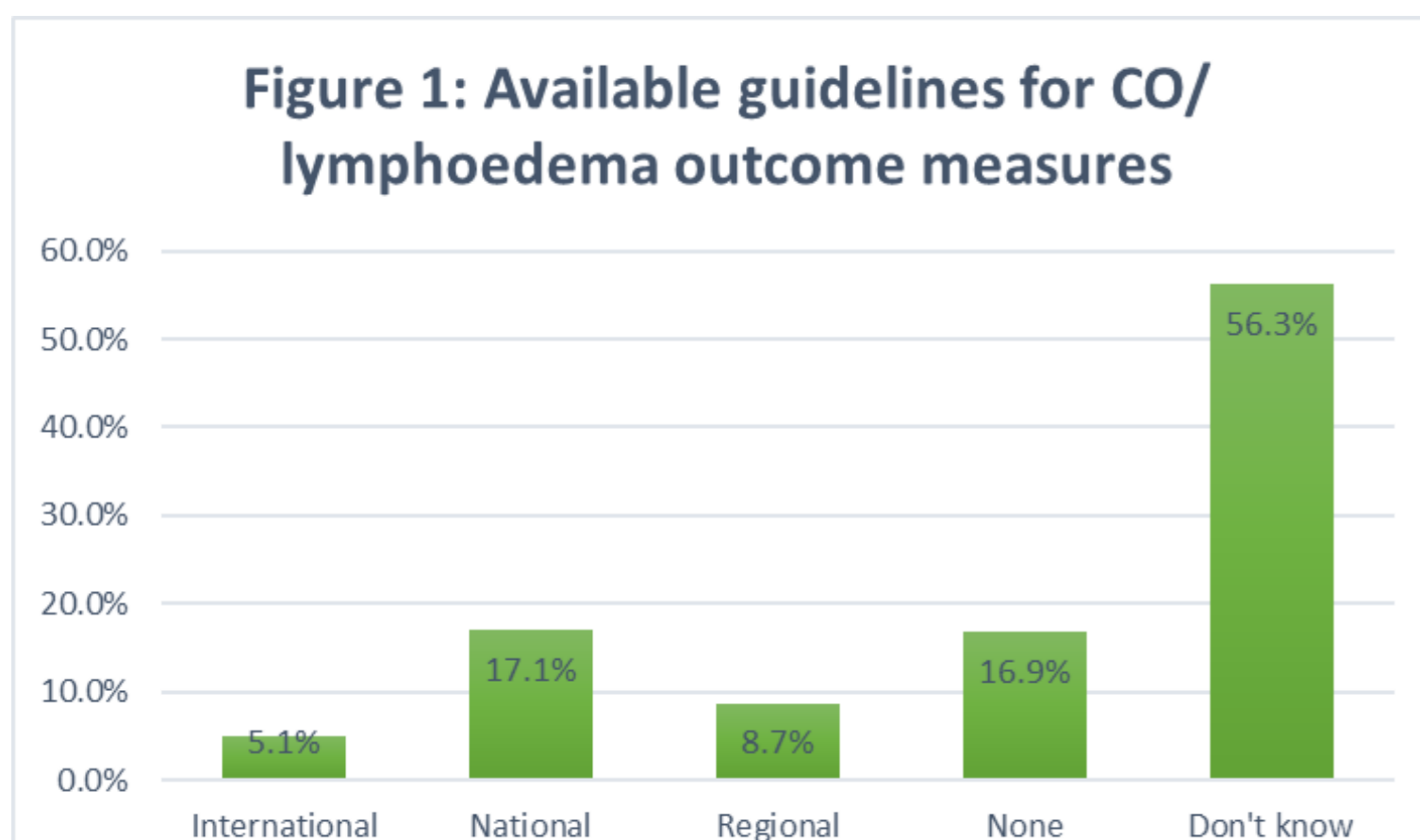
- ❖ Steering group with individual National Frameworks
- ❖ Agreement on national plans for implementation



RESULTS FROM ILF-COM DENMARK

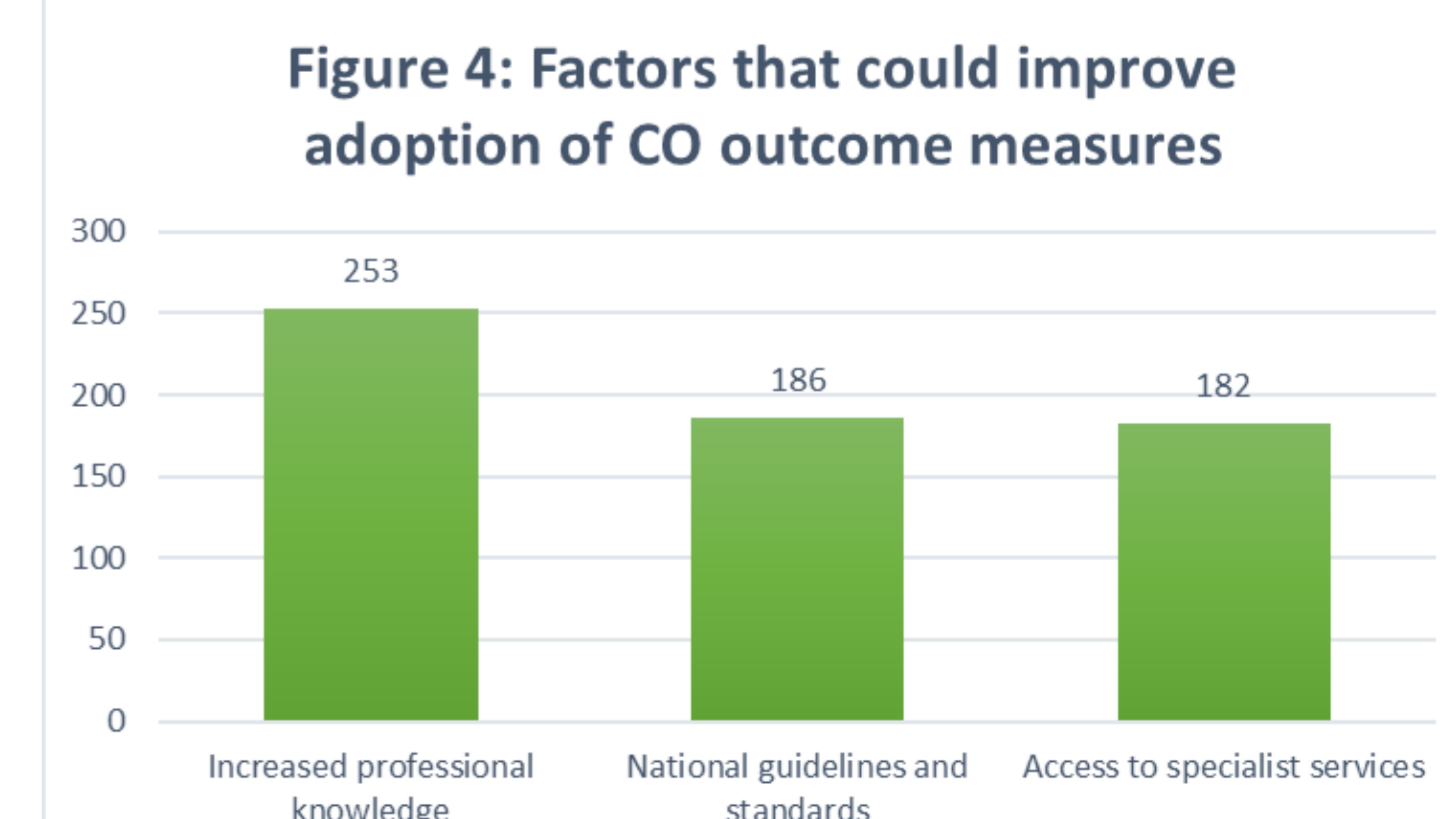
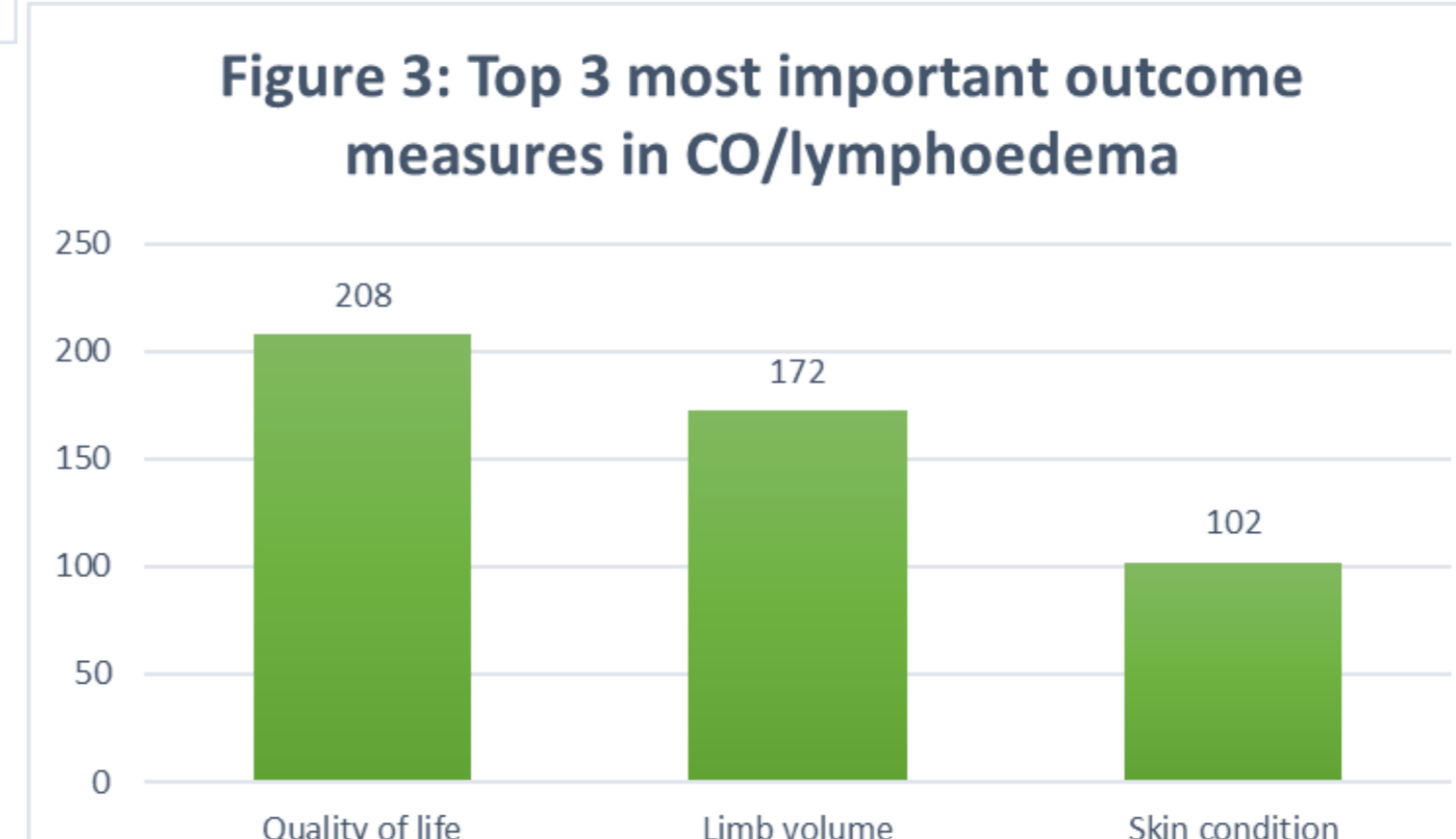
The survey was completed by **442** respondents, of those **43%** were patients.

Overall 56.7% respondents did not know whether there are any guidelines for chronic oedema/ lymphoedema outcomes measures in Denmark (fig 1)..



About 55% of respondents indicated that outcome of treatment is always measured or is measured sometimes (fig 2).

Quality of life status, limb volume and mobility status were perceived as the top 3 most important outcomes in chronic oedema/ lymphoedema that should be measured (fig 3).



Respondents indicated that the most important factors that could improve the adoption of chronic oedema/ lymphoedema measures are: increased professional knowledge, national guidelines and standards, and access to specialist services (fig 4).