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
  - German
  - Dutch
  - Italian
  - English
  - Japanese
  - French
  - 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

Implementation of survey (finish 31st March 2019)
Report of findings to Frameworks (22nd April 2019)
Posters produced for ILF Conference in Chicago (24th May 2019)
Chicago meeting: Planning the way forward (13th-15th June 2019)

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