ILF-COM reporting from Australia

Linda Khong * Physiotherapist & Lymphoedema Therapist
Gillian Buckley # Physiotherapist & Lymphoedema Therapist
Sally James. **Clinical Nurse Consultant – Wound & Lymphoedema

INTRODUCTION

- Clinicians & clients often lament the lack of an universal standard to evaluate the outcomes of treatment for chronic oedema & lymphoedema.
- In Australia, there are a number of regional and national organisations actively working towards reducing the burden of lymphoedema within our community by ensuring timely access to affordable lymphoedema services. These groups continue to lobby Australian federal and state governments, health professionals, researchers and health providers.
- A group of three health professionals in Australia decided to participate in the ILF-COM study to progress towards developing an internationally agreed set of outcome measures for patients with this condition.

AIMS

Our group aimed to participate in the third aspect of ILF-COM, to develop an internationally agreed set of outcome measures for patients with the condition for use in clinical practice & research. This would be achieved through the dissemination of the project's survey monkey to varied groups and individuals associated with chronic oedema / lymphoedema in Australia.

METHODS

- Local steering group of 3 health professionals formed in November 2018.
- Collation of potential groups / stakeholders identified to participate in the on-line survey from ILF-COM considered.
- Final planned groups & individuals, spread over many Australian states, approached and provided with information and link to survey.
- Participants also informed the survey could be passed on to others associated with chronic oedema / lymphoedema.
- Survey closed March 31, 2019.
- Data received from ILF-COM.

METHOD-SETTING

The groups who participated included:

- Professional lymphoedema & wound care associated groups and individuals.
- Patient support groups- lymphoedema/cancer
- Industry suppliers for compression therapy & wound care

RESULTS- Participants

- 688 people took part in the ILF-COM survey monkey in Australia.
- 54% of these were patients.

- 266 respondents identified as health professionals, of which the majority (42%) were physiotherapists. The rest were occupational therapists (26%), nurses (17%), medical doctors (4%) and other professions (11%).
- Half (53%) of the health professionals work in the public and 47% in the private.
- Majority were hospital-based.

RESULTS- Outcome measures

- Most (45%) of the health professionals responded that they do some outcome measures of chronic oedema (Figure 1).
- More than 54% of all respondents did not know if there was any guidelines on outcome measures available in Australia

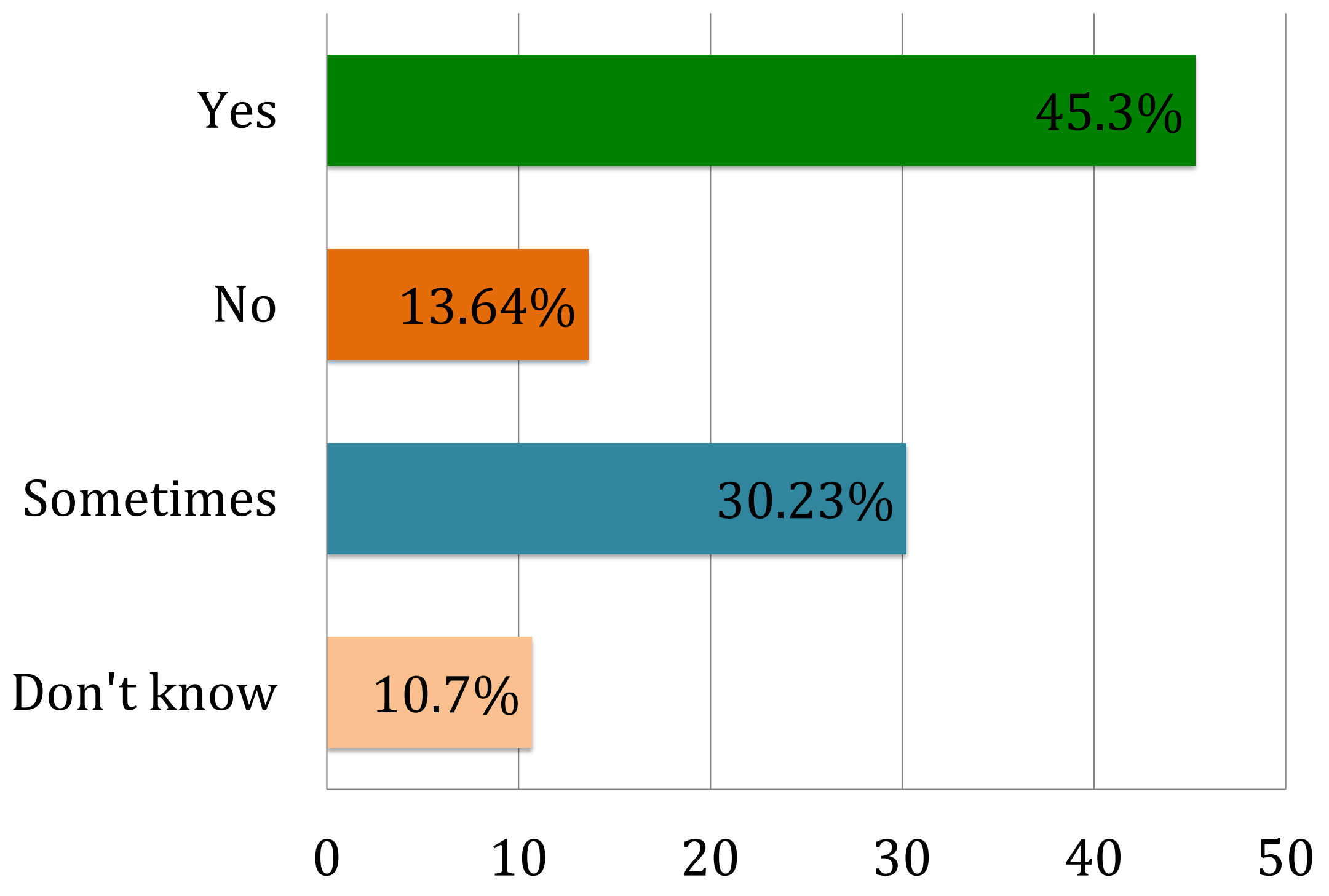

Figure 1: Is chronic oedema/lymphoedema outcome of treatment measured

- The five most frequently used outcome measures reported were:
  - ➢ Circumference measurements (72%)
  - ➢ Mobility status (57%)
  - ➢ Photographs (56%)
  - ➢ Episodes of cellulitis (54%)
  - ➢ Bioimpedence (49%)

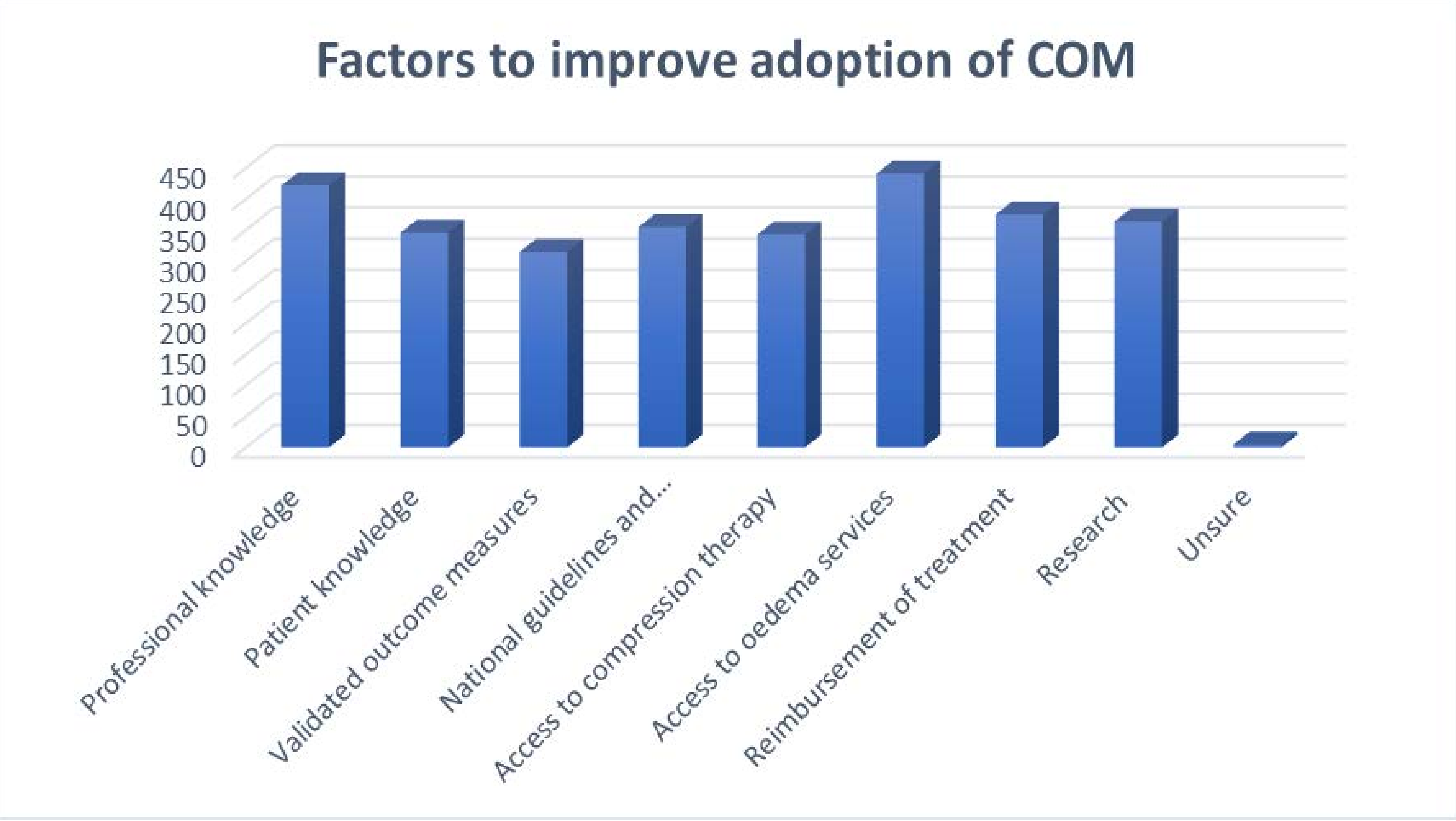

Figure 3: Factors that could improve adoption of COM

- Amongst several outcome measures, the respondents deemed the following as the most important outcome measure:
  - ➢ Limb Volume (58%)
  - ➢ Quality of Life (54%)
- However, compared to what is normally measured/practised, the top three measures deemed for successful chronic oedema outcomes reported were: (see **Figure 2**)
  - ➢ Stable limb volume
  - ➢ Quality of Life status
  - ➢ Ability to self-manage

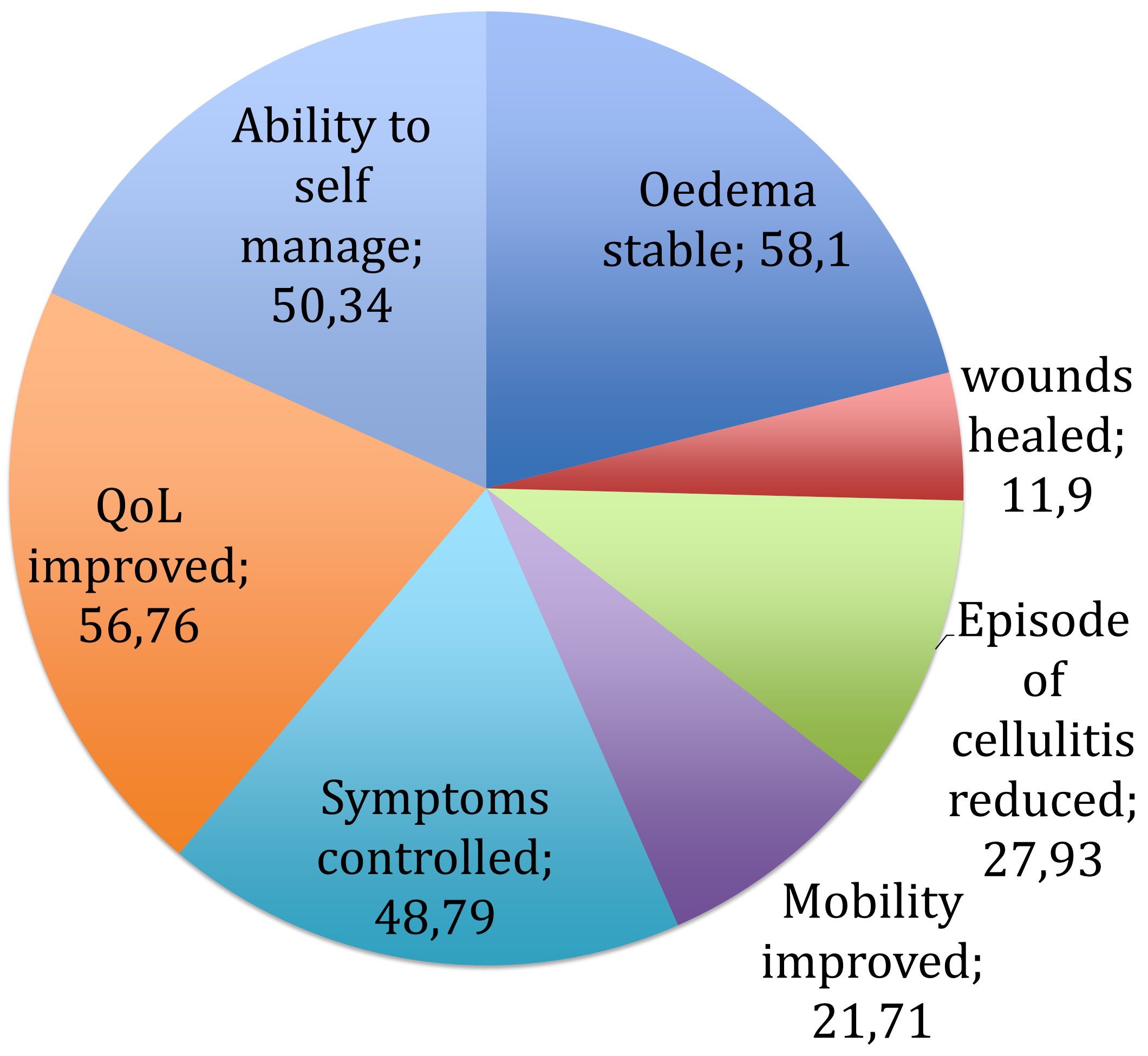

Figure 2: What do you believe is a successful chronic oedema / lymphoedema treatment

- **Figure 3** illustrates the range of factors that could improve the adoption of chronic outcome measures. The most common factor chosen was "access to specialist chronic oedema/lympheodema services".

CONCLUSIONS

The findings from the Australian ILF-COM survey will be discussed with the other participating frameworks in Chicago with the aim of prioritizing the issues and to progress to the next level.

* Sir Charles Gairdner Hospital; LK Lymphoedema Centre

#

**