

ILF-COM reporting from the Dutch Lymphoedema & Lipoedema Framework (NLNet), the Netherlands

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Introduction

The Chronic Oedema Outcome Measure (ILF-COM) project is aiming to develop an internationally agreed set of outcome measures for patients with chronic oedema.

The ILF has identified several key priority areas that are inhibiting the recognition of chronic oedema as a major, emerging public health care problem. This includes the need for:

- International epidemiology to provide evidence of the size and impact on health care services.
- International standards and methods for assessing and reporting the outcome of treatment of patients with different forms of chronic oedema.

Aim

The aim of the ILF-COM study in the Netherlands was to gain insight into the perspective of healthcare professionals and patients on the quality of healthcare services with regards to the types of treatment, general assessment of outcomes, reimbursement of treatments and medical devices for chronic oedema.

Methods

The ILF COM outcome questionnaire was sent out in the Netherlands using the database of NLNet (patients and professionals), NVFL (Dutch oedema physical therapist association) and NVH (Dutch skintherapist association), with the request to reshare the link with other patients and therapist/professionals within the field of lymphology.

Demographics

This resulted in 1166 participants completing the questionnaire. Of the 1166 participants, 290 were identified as health care professionals.

Demographics n=1,166

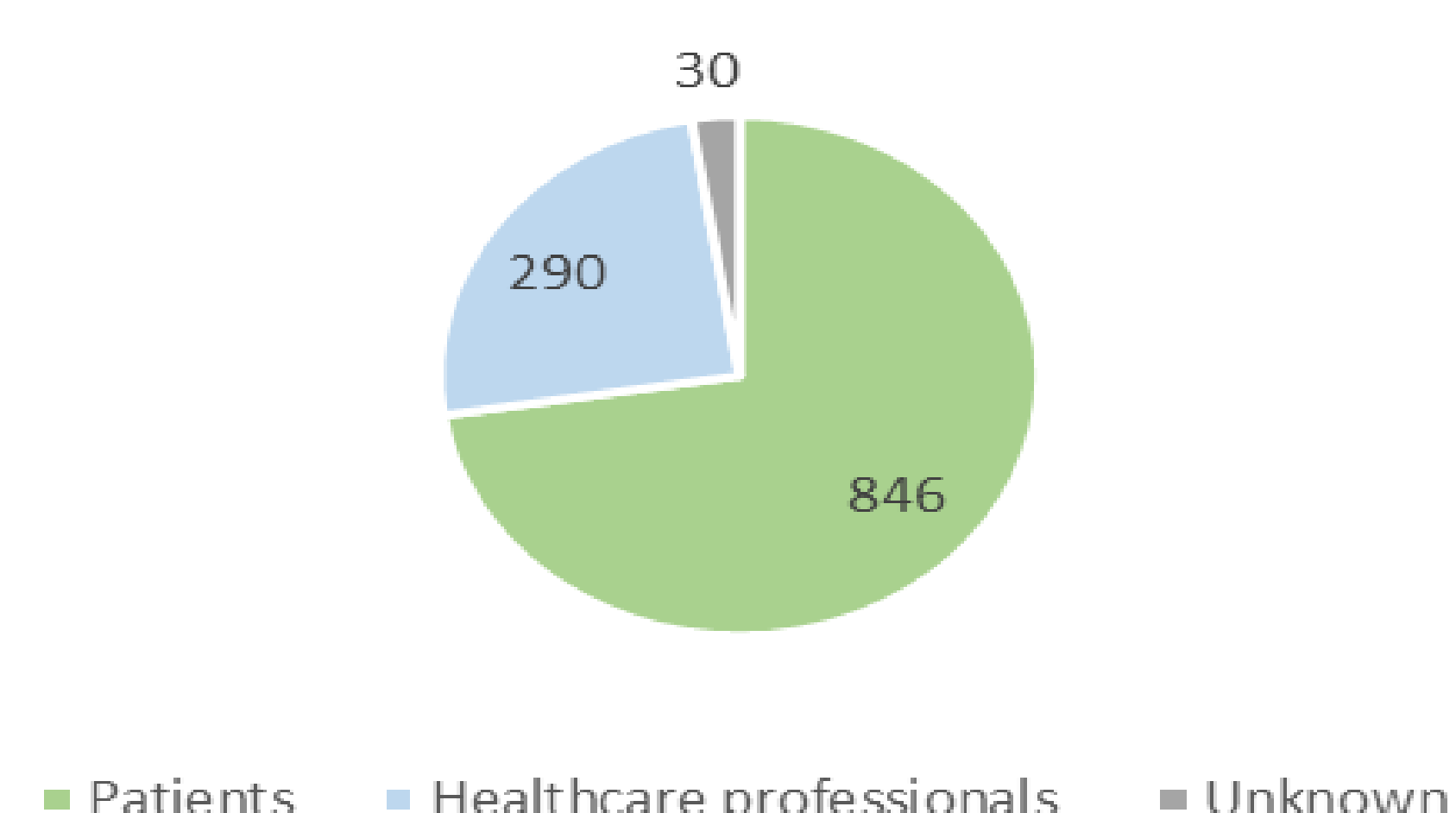


Figure 1: Demographic information the Netherlands

Results

Outcome of treatment measured

16% of the participants answered that chronic oedema or lymphoedema outcome of treatment is not measured, 14% answered that it is only sometimes measured and 26% is unsure whether measurements are done.

Is chronic oedema/ lymphoedema outcome of treatment measured n=1,045

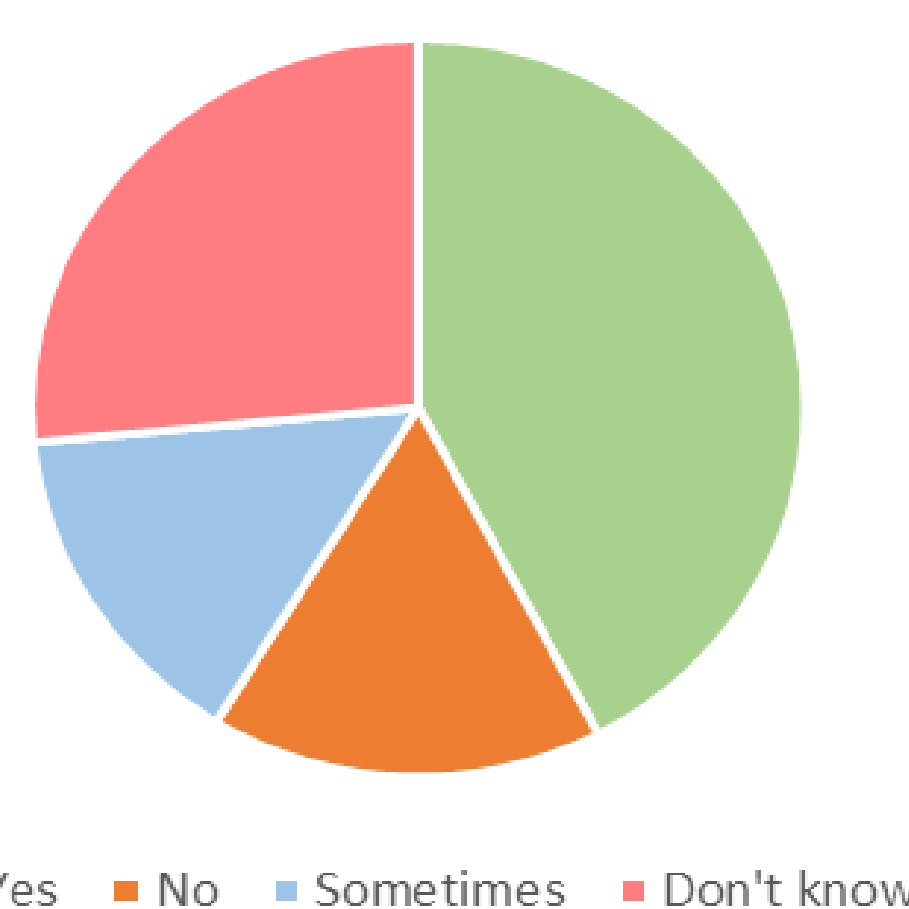


Figure 2: Outcome of treatment measured

Awareness of guidelines

59% of the respondents are not aware of guidelines for chronic oedema/ lymphoedema outcome measures.

Awareness of guidelines for chronic oedema/ lymphoedema outcome measures

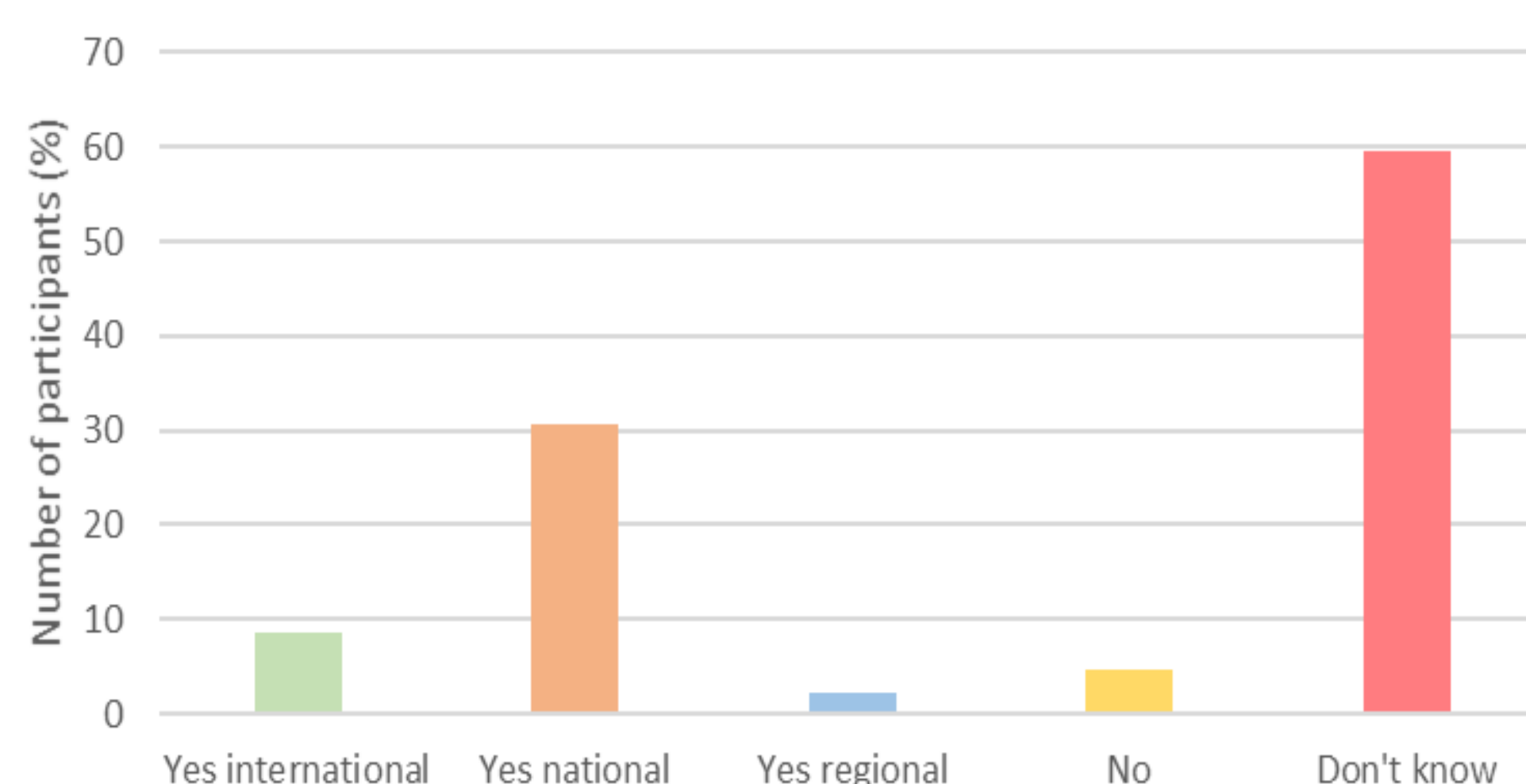


Figure 3: Awareness of chronic oedema/ lymphoedema guidelines

Outcome measures

In the Dutch survey, limb circumference is the 5th most frequently used outcome measure (56,18%), more frequently used are:

- Pain (75,66%)
- Mobility (73,3%)
- QOL (62,17%)
- BMI/Weight (61,80%)

The most important outcome measures that should be recorded according to patients and professionals are:

1. QOL
2. Limb volume
3. Mobility



The outcome measures considered to be indicative of the success of the treatment are:

1. Limb volume is stable
2. QOL is improved
3. Symptoms are controlled



Factors improving adoption of outcome measures

Respondents are aware that outcome measures are important and think that the following factors can contribute to improving the adoption of chronic oedema outcome measures:

- Increased professional knowledge (59,91%), - Reimbursement of treatment (52,07%),
- Increased patient knowledge (45,16%),
- Clinical and cost-effective research in chronic oedema/ lymphoedema treatment (43,09%)

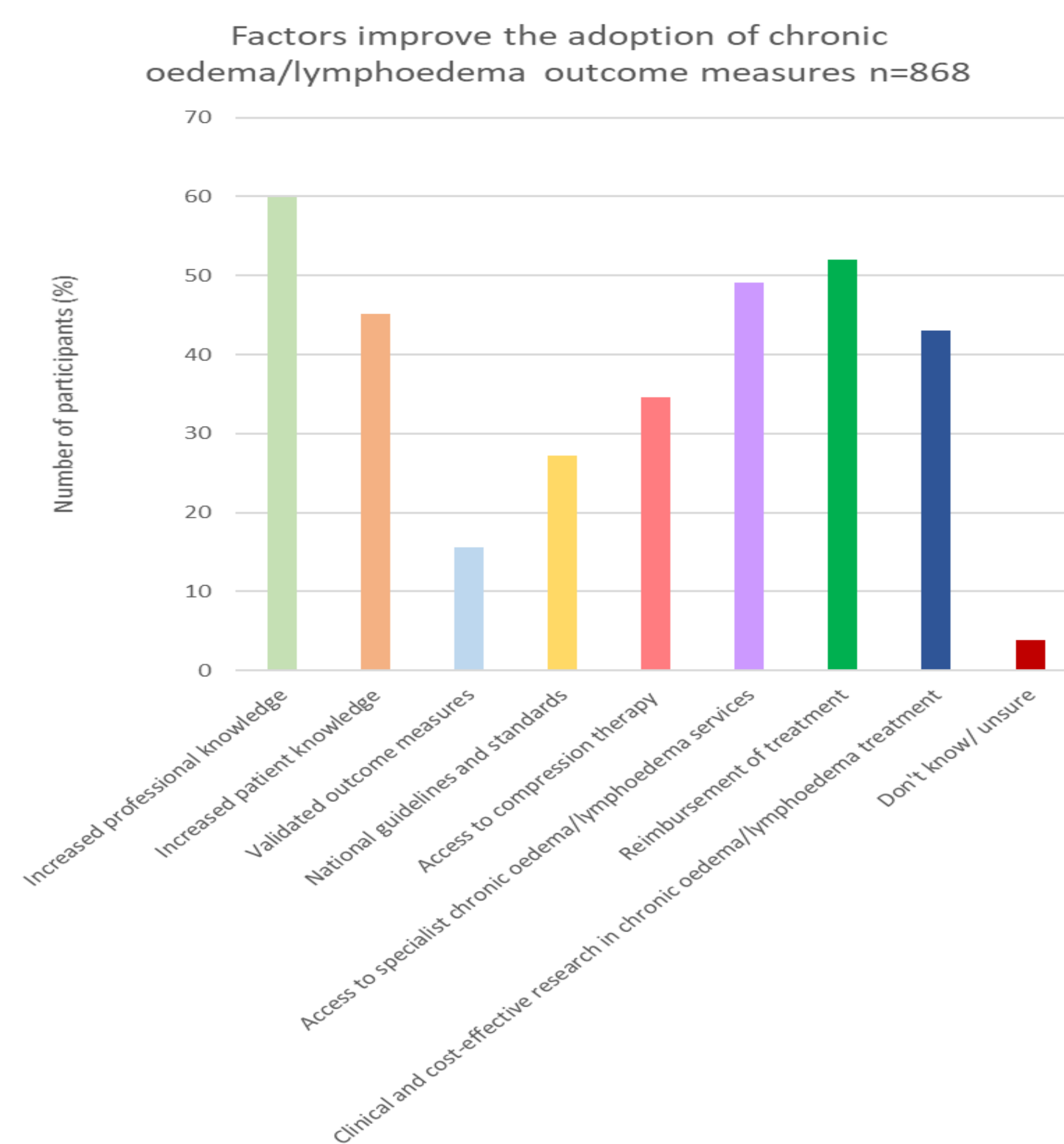


Figure 4: Factors improving adoption of chronic oedema/ lymphoedema guidelines

Self-management

In the Netherlands, there is a focus on the ability of self-management, and this should be part of the treatment a patient gets. However, only 35,24% of the respondents mentioned the ability to self-manage as an outcome measure.

N=1166

A very special thanks to all participants of this survey and for everybody who made it possible to achieve this number of participants!

Recommendations:

Implementation of guidelines:

- adoption of outcome measures
- Focusing more on ICF rather than limb size

Regarding self-management

- Introducing pain rehabilitation strategies
- Focus on patient empowerment
- Full reimbursement of compression devices as needed