

# ILF (International Lymphoedema Framework) CHRONIC OEDEMA OUTCOMES SURVEY-RESULTS FROM TURKEY

**Pınar Borman MD, Aysegul Yaman MD, Esra Gizem Koyuncu MD,  
Figen Ayhan MD, Sibel Unsal MD, Sibel Eyigor MD, Muge Kepekci MD, Secil Vural MD,  
Ayse Arikan Dönmez RN, Sevil Ceyhan Doğan MD, Burcu Duyur Çakıt MD**



## INTRODUCTION

Lymphedema and chronic edema is a major health care problem in both developed and nondeveloped countries. The International Lymphoedema Framework (ILF) recognised that a lack of clarity about outcome measures for people with lymphoedema and related disorders was contributing to a lack of development of services and reimbursement of care. The Chronic Oedema Outcome Measure (ILF-COM) project is aiming to develop an internationally agreed set of outcome measures for patients with chronic oedema. In addition this project aims to attract attention the lack of agreed international standards and methods for assessing and reporting the outcome of treatment of patients with different forms of chronic oedema. The changes in limb volume most commonly used for outcome measure in chronic oedema or lymphedema might be evaluated by many different methods and there is a lack of standardisation on application. Comparison of the studies is almost impossible due to the variety of approaches. The AIM of this study was to determine the use of outcome measures in chronic oedema or lymphedema and reimbursement issues for lymphedema treatment in Turkey. Results from the survey will indicate the different approaches for the use of outcome measures according to different countries and cultures. The data will be shared and used to develop a strategic approach to outcome measures by the ILF over the next years. In addition we believe that the data will also be informative for developing national health policies and reimbursement procedures in treatment and follow-up of patients with lymphedema in Turkey

## METHODS

Development of the Survey Tool A stakeholder meeting with professionals involved in lymphoedema management, patients and the medical device industry was carried out in May 2018 in Copenhagen, Denmark. An open-space meeting approach was used to scope the questionnaire from the priority issues established. The questionnaire was reviewed by international experts and prepared for piloting. The pilot questionnaire was completed at the Danish Lymphoedema Framework Conference in October 2018 and any questions requiring clarity were re-formulated. The questionnaire was prepared for translation into English, French, German, Italian, Japanese, Turkish, and Dutch. The Turkish questionnaire was prepared through a linguistic translation and back translation. Any terms requiring clarification were discussed with the project team (1). The Turkish survey was uploaded on to Survey Monkey on 6th of December. Survey Monkey was chosen as it provides a simple method of reporting. The Survey was open up to 31th March 2019. The survey has been developed for completion by a range of groups including; patients/patient organisations/charities, clinicians (both specialist and generalist practitioners), academics, health agencies and health services and the medical device industry. The participants were asked to answer the 5-minute web-survey, including 14 questions. In addition to their demographical and logistic properties, the questionnaire elicited data on set of outcome measures for patients with chronic oedema and lack of development of services and reimbursement of care. Local Steering Group There are 2 main institutions related with Lymphedema in Turkey: Anatolian Lymphedema Association and Hacettepe University Lymphedema Practice and Research Center. Therefore the executive committee members and delegates of these 2 institutions (from different parts of Turkey, who are working as health professionals in centers that are capable in the management of lymphedema) were informed about the survey and kindly asked to send the survey to their colleagues, patients and staff working within medical device industry. There were 8 health professionals from 5 different centers, except the local survey coordinator (PB). In addition the patients were involved during the '6th of March-World Lymphedema Awareness day' educational and social programs. Also the survey was placed on the website and facebook of Anatolian (Turkish) Lymphedema Association and an announcement for invitation to the survey was sent to the members.

## RESULTS

Five hundred ninety nine participants completed the survey. 227 of the participants were patients and 370 of the participants were healthcare professionals. One hundred and eighty-seven of the participants were

medical doctors, mostly physiatrists (specialist of PMR), while 110 of the participants were physiotherapists, 1 occupational therapist, 55 were nurses and 16 were specified as other. When we questioned them about their workplaces, we found out that 67.7% of them worked in public hospitals and 30.75% of them were working in academic institutions according to the type of their facility. The percentage of the healthcare professionals who said that they treated patients with chronic oedema/ lymphedema was 72.1%. The number of participants who work within the medical device and pharmaceutical industry was 57 (9.1%). The percentage of the participants who said that chronic oedema/lymphoedema outcome of treatment is measured was only 45.2%, while 23.2% of the participants replied that chronic oedema/lymphoedema outcome of treatment is not measured in their practice. When the participants were asked whether there are any guidelines for chronic oedema/lymphoedema outcome measures in our country, most of them (40.5%) replied as 'I don't know' and 24.6% of them replied as 'No'. The scales that health professionals and industry use to determine the outcome in daily practice are given on Table 1. The most commonly used outcome measure was circumferential measurements followed by symptoms and quality of life issues.

**Table 1. The scales that health professionals and industry use to determine the outcome in daily practice**

	Percent	N=372
ISL staging	20.41%	60
CEAP classification	6.12%	18
Lymph-ICF	10.54%	31
Circumference only without calculating volume	27.89%	92
Circumference measurements	75.17%	291
Perometer/ Infrared imaging	4.42%	13
Water displacement method	5.44%	16
Photographs	38.44%	118
Moisture meter	1.02%	3
Ultrasound	12.59%	37
Dexa scan	1.70%	5
MRI	4.08%	12
Bioimpedance	3.06%	9
Lymphoscintigraphy	17.69%	52
Indocyanine Green Lymphography (ICG)	1.70%	5
Wound type	16.33%	48
Wound size	17.35%	51
Episodes of cellulitis/erysipelas	12.93%	38
Hospital admission linked to chronic oedema/ lymphoedema	11.90%	35
Complications of treatment	19.39%	57
Weight/ BMI	27.21%	80
Quality of life	38.44%	113
Pain	40.14%	118
Mobility	27.21%	80
Patient adherence to treatment	29.59%	87

When we asked whether the chronic oedema/ lymphoedema treatment was funded in our country, 55.65% of the participants said that some aspects of treatment were funded while 24.83% of them have no information on this issue. Table 2 indicates the reimbursements and the treatments that should be paid by the patients in their health system.

**Table 2. Treatments that should be paid by the patients according to health system.**

	Percent	N=244
Skin care advice	21.31%	52
Wound dressing	11.07%	27
Antibiotic	7.38%	18
Massage (including lymphatic drainage)	22.13%	54
Compression garment	63.11%	154
Compression bandage	71.31%	174
Compression wrap	61.89%	151
Night bandages	55.33%	135
Pneumatic compression pump	27.46%	67
Lymphoedema surgery	20.08%	49
Liposuction	23.77%	58
Exercise	8.20%	20
Kinesio taping	48.36%	118
Psychologist	15.98%	39
Other	3.69%	9

The participants stated that the most important three outcomes in chronic oedema / lymphoedema that should be measured were; quality of life status (63.64%) limb volume (61.11%) patient satisfaction with treatment (26.52%) as well as the mobility status (26.52%). The participants believed that three successful outcomes for chronic oedema / lymphoedema treatment include improvement of quality of life (68.18%), stabilization of limb volume or oedema (56.06%) and control of symptoms (45.71%). Additionally the participants remarked that the three factors indicating that treatment is ineffective or failing were increased limb volume and oedema (69.19%), symptoms uncontrolled (e.g. pain, heaviness)(50%) and requirement for repeated intensive treatment (42.68%). Finally the factors improving the adoption of chronic edema / lymphedema is shown in Table 3. The most common factors that would improve the adoption of lymphedema outcome measures were determined as; increased patient and health Professional knowledge and reimbursement of treatments, as well as national guidelines and standards.

**Table 3. The factors improving the adoption of chronic edema / lymphedema outcome measures**

	Percent	N=386
Increased professional knowledge	56.99%	220
Increased patient knowledge	63.21%	244
Validated outcome measures	32.64%	126
National guidelines and standards	41.19%	159
Access to compression therapy	30.83%	119
Access to specialist chronic oedema/ lymphoedema services	32.38%	125
Reimbursement of treatment	46.37%	179
Clinical and cost-effective research in chronic oedema/ lymphoedema treatment	32.38%	125
Don't know/ unsure	5.96%	23

## CONCLUSION

Most of the attendants were health professionals in Turkey survey. The outcome of treatment was measured by only 45.2% of the attendants and the most commonly used method was circumferential measurements. More than half of the participants declared that some aspects of treatment were funded while 25% of them have no information on this issue. The most important three outcomes were determined as quality of life status, limb volume and patient satisfaction with treatment. Therefore the improvement of standardization of quality of life and stabilization of limb volume or oedema, as well as control of symptoms are needed. In follow-ups; the evaluation of increased limb volume and oedema, uncontrolled symptoms and requirement for intensive treatment are of importance. In conclusion; there is a need for the standardization of outcome measures and follow-up parameters; particularly in circumferential measurements, quality of life issues and intensive treatment indications. International and national guidelines will help to determine these issues. We believe our and other frameworks' outcome measure data will help to better understand how clinicians determine the progress of a treatment and how outcome measures could be standardised to achieve better patient outcomes. The results will be essential in supporting the introduction of evidence-based practice and enabling our national framework to argue for appropriate financing and reimbursement. We hope this evidence-based data will also change the national policies for the care of Turkish patients with lymphedema or chronic edema.

## REFERENCES

[www.lympho.org](http://www.lympho.org)