Appendix Overview of the different variables and outcomes in the SurLym trial, the assessment method and the description of the method

Variable	Assessment method; description of method
Descriptives (15 min)	
Demographics	
Age (in years)	Medical file
Gender (man vs women), smoking status (smoking vs non-smoking), living status (alone vs together)	Interview
Body height (in m)	Stadiometer
Comorbidity (yes vs no)	Self-reported questionnaire developed by IDEWE (= external institute for prevention and protection at work); presence of wound by accident, of disease of musculoskeletal, circulatory, respiratory, neurological, digestive, urinary system, of disease of blood or skin, of mental or metabolic problems or of tumor (yes vs no)
Educational level (low vs high)	Interview; lower education = primary and secondary school, higher education = non-university higher and university
Anxiety and depression (0-42)	Self-reported Hospital Anxiety and Depression Scale; 14 statements regarding anxiety and depression with score 0-3

Characteristics of lymphoedema and its treatment	
Duration of lymphoedema (in months)	Interview
Localisation of lymphoedema (yes vs no)	Inspection; for upper limb lymphoedema: hand/ lower arm/ upper arm/ trunk or for lower limb lymphoedema: foot/ lower leg/ upper leg/ pelvic/ genital region, unilateral/ bilateral, site of lymphoedema followed in trial: left/ right
Pitting status (yes vs no)	Palpation; for upper limb lymphoedema: hand/ lower arm/ upper arm/ trunk or for lower limb lymphoedema: Foot/ lower leg/ upper leg/ pelvic/ genital region
Stage of lymphoedema (1 vs 2a vs 2b)	Inspection en palpation; Stage 1= pitting oedema that disappears with limb elevation (= reversible), 2a= pitting oedema that does not disappear completely with limb elevation, 2b= further decrease of pitting and accumulation of fat tissue
Primary or secondary lymphoedema	Interview and medical file; Primary = congenital; secondary = acquired after cancer-treatment (and type of cancer), trauma, surgery, infection
History of conservative treatment	Self-reported questionnaire (developed by author); Information regarding 1) physical therapy: number of years, number of sessions last month/ year, content, 2) intensive treatment: where, how often, 3) other care giver, 4) self-management
Primary outcome	

Self-reported questionnaire (5 min)	
Lymphoedema-specific QoL (0-100)	Lymph-ICF questionnaire Dutch or French version for upper or lower limb lymphoedema;(12-15) 28 and 29 questions on 11-point scale between 0-10, total score between 0-100 (0= no problems in functioning related to the development of lymphoedema)
Secondary outcomes	
Self-reported questionnaires (60 min)	
Lymphoedema-specific QoL (0-100)	See primary outcome; in addition, score on 5 domains, i.e. physical function, mental function, household, mobility and life and social life domain (0-100)
Duration (key secondary outcome) and experience of wearing compression garment	ICC compression questionnaire;(16) Dosage (0-168 hours/ week), application/ removing compression (0-10), comfort (score between 0-10), complication (score between 0-10), general experience (0-10)
Health related QoL	EuroQol-5D-5L;(17) 5 items about mobility, self-care, activity, pain and anxiety (each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems), range between -0.33 for situation '33333' (severe problems on all items) and 1 for situation '11111' (complete healthy)
Work capacity and ability	Work Productivity and Activity Impairment questionnaire (WPAI-GH);(18) Impairment while working due to health, overall work impairment due to health, activity impairment due to health (%)

	QuickScan 18 – short version;(19) Chance for successful socio-professional reintegration (score between 0 certainly not and 5 certainly yes)
Physical activity level (MET-hours a week)	International Physical Activity Questionnaire;(20) 7 questions about hours a week of vigorous (8 MET), moderate (4 MET) and walking activities (3.3 MET), and sitting time
Costs related to lymphoedema and its treatment (in euro)	Study-specific questionnaire completed monthly by the patient; collection of patient and health care costs for material (such as compression or exercise material), medication, diagnostics or care giver (similar questionnaire as for Effort-BCRL trial)
Usual care & self-management §, including need for intensive treatment	Study-specific usual care & self-management questionnaire completed monthly by the patient; information regarding 1) physical therapy: number of sessions, duration and content; 2) intensive treatment: where, number of sessions, content; 3) other care giver; 4) self-management: number of days of each modality
Assessment (60 min)	
Limb volume (key secondary outcome)	Circumference measurements every 4 cm with perimeter;(21-24) limb volume is calculated with formula of truncated cone, in participants with upper limb lymphoedema: assessment of affected and non-affected arm; outcome is excessive arm volume (%) = (volume $_{\text{AFFECTED ARM}}$ – volume $_{\text{UNAFFECTED ARM}}$/ volume $_{\text{UNAFFECTED ARM}}$) x 100, in participants with lower limb lymphoedema: assessment of affected leg (= leg that is followed in trial); outcome is whole leg volume (in ml)
Hand/ foot volume	Water displacement method of hand or foot;(22, 25) volume is the mass of the displaced water, in participants with upper limb lymphoedema: assessment of affected and non-affected hand, outcome is excessive hand volume (%); in participants with lower limb lymphoedema: assessment of affected foot, outcome is foot volume (in ml)

Failure to reduce hours a day of wearing compression stocking (yes, not able vs no, able)	Assessor determines whether participant is able to reduce the hours a day of wearing the compression garment as stated by the protocol (see figure 1, M7-12); Not able = excessive arm volume/ leg volume increased more than the smallest real difference, i.e. 5% or more compared to baseline(14)
Body weight (in kg)	Scale
Infection previous 18 months (number)	Interview
Recurrence of cancer (yes/ no)	Interview and medical file; only collected in the group with history of cancer
Adverse events (whole group) and complications of surgery (in intervention group) (yes/ no)	Interview and medical file; registration of adverse events related to pre-surgical or study-specific investigations: ICG fluoroscopy, lymphoscintigraphy, lymph MRI, CT angiography, of complications of reconstructive lymphatic surgery: 1) in general blue spot, wound healing problem, infection of wound, decrease of sensibility around wound, erysipelas of limb, deep venous thrombosis, 2) LNT-specific seroma, lymphocele, donor site lymphoedema, loss of flap
Costs related to lymphoedema and its treatment (in euro)	Study-specific questionnaire completed by the compression specialist after delivery of compression material; registration of company, compression product, region of compression, type, compression class, cost for health insurance/ patient Inter Mutuality Agency (IMA) database (= agency collecting data from different mutual health insurance companies), based on national number of the study participant
Lymphatic transport	

ICG fluoroscopy (60 min)	ICG fluoroscopy;(26) 0.2 ml dilution of ICG/ aqua/ NaCl is injected intradermally in 1st and 4th web of affected hand or foot; procedure consist of 3 minutes of rest, 5 minutes of stimulation and registration of outcomes (=early phase) and a break until 90 minutes post-injection and again registration of outcomes (= late phase); registration of following outcomes: 1) transport out of injection sites (yes/ no), 2) dermal rerouting (no, splash, stardust and diffuse for predefined regions on arm/ leg), 3) transport out of dermal rerouting, 4) lymph nodes (yes/ no)
Lymphoscintigraphy (60 min)	Lymphoscintigraphy;(27, 28) 55MBq ^{99m}Tc nanocolloids are injected intradermally in 1st web of both hands or feet; procedure consist of following steps: 1) 25 minutes of rest, 2) 5 minutes of arm/ leg cycling and 3) early phase acquisition; 4) 60 minutes break; 5) late phase acquisition; following images are made: before and after rest an image of injection sites and at the end (outcome: extraction out of injection sites in %), after rest, cycling and at the end a mini whole body (outcomes: number of lymph nodes, intensity of lymph collectors, intensity of dermal backflow, presence of lymph collaterals), during 25 minutes of rest dynamic images of axilla/ arm or groin/ leg (outcomes: arrival time and uptake in axilla/ inguinal region in %); in addition transport index is determined, based on transport kinetics, distribution of tracer, time to visualize lymph nodes and visualization of lymph nodes/ vessels

§ No secondary outcome