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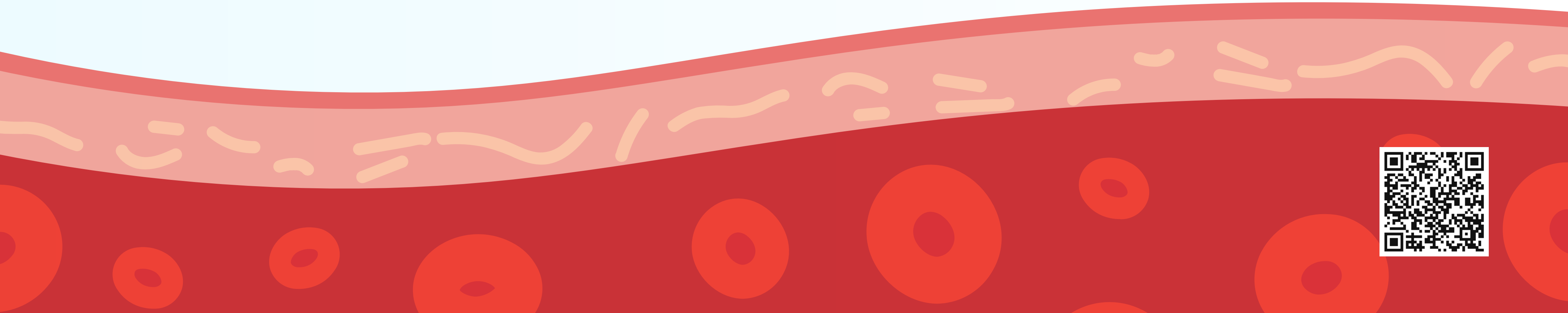
# Common & Clinical Outcomes Dataset

## ADULTS AND CHILDREN

*For Paediatric and Primary Lymphoedema (PPL)*



# Introduction

This dataset was developed and validated by the Paediatric and Primary Lymphoedema Working Group (PPL-WG) of VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, as part of its mission to harmonise and improve care across Europe.

We recommend evaluating the patient at one of the first contacts in the clinic/ practice, and before and after a certain intervention (such as intensive treatment, surgery, ...) is performed, and again after 1 year of follow-up.

Some outcomes differ between adults and children.

This outcome dataset is effectively a  minimum dataset that is recommended for paediatric and primary lymphoedema patients with upper and/ or lower limb lymphoedema. Lymphoedema affecting other anatomical sites (e.g. genital lymphoedema) is not evaluated in depth. It is the choice of the healthcare provider to add some local outcomes if they wish.

Items required only for the FAIR Registry, which are not also part of the outcomes dataset, are marked with an asterisk (*).

**Common & Clinical Outcomes Data Set: ADULTS & CHILDREN**

<table>
<tr><td>Date of assessment (DD.MM.YYYY)</td><td colspan="7">…</td></tr>
<tr><td>Date of birth (DD.MM.YYYY)</td><td colspan="7">…</td></tr>
<tr><td>Gender</td><td colspan="7">M/ F/ undetermined/ unknown</td></tr>
<tr><td>First contact with your specialised center (DD.MM.YYYY)</td><td colspan="7">…</td></tr>
<tr><td>Date of onset of lymphoedema (DD.MM.YYYY) – if exact date is unknown, put the 1st day of year</td><td colspan="7">…</td></tr>
<tr><td>Age of onset of lymphoedema (y)*</td><td colspan="7">…</td></tr>
<tr><td>Age of diagnosis (y)*</td><td colspan="7">…</td></tr>
<tr><td>Lymphoedema diagnosis (e.g. Hennekam)</td><td colspan="7">…</td></tr>
<tr><td>Orphanet code*</td><td colspan="7">…</td></tr>
<tr><td>Genetic testing*</td><td colspan="7">Yes / no / unknown</td></tr>
<tr><td>Region of lymphoedema (select all that apply)</td><td>Arm<br>Left/ right</td><td>Leg<br>Left/ right</td><td>Face</td><td>Trunk</td><td>Abdomen</td><td>Genital region</td><td>Systemic involvement</td></tr>
<tr><td>Treatment at presentation (select all that apply)</td><td colspan="3">None</td><td colspan="2">Intensive treatment (in short period of time, normally 1-4 weeks with a maximum of 3 months)</td><td colspan="2">Maintenance treatment (can be first treatment if no intensive treatment is necessary)</td></tr>
</table>

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Compression garment | Bandage | Wrap | Pneumatic compression | Exercises | Skin and wound care | Weight management and specific diet | Manual lymph drainage | Psychosocial support |
| | Prophylactic antibiotics | Other: … | | | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| | If compression garment: | CCL (if different compression pieces, highest CCL): … | Flatknitted/ roundknitted | Hand glove/ arm sleeve | Toecap/ knee stocking/ thigh stocking/ pantyhose/ Bermuda pants |
| | If bandage: | Non-elastic (short-stretch)/ elastic (long-stretch) | Single component/ multicomponent | | |
| Lymphatic surgery (select all that apply) | None | Lymphovenous anastomosis | Vascularised lymph node transfer | Liposuction | Debulking / reduction |

| | |
|---|---|
| Height (cm) | … |
| Weight (Kg) | … |
| BMI | … |

| | | | |
|---|---|---|---|
| **Limb volume measurement:** Select type – 3D scanning/ perometry/ circumferential mmts/ water displacement | Left Leg (mls): … | Right Leg (mls): … | Difference (mls): … |
| | Left Arm (mls): … | Right Arm (mls): … | Difference (mls): … |

| | | | |
|---|---|---|---|
| Hand / Foot measurement: Select type – figure of eight (cm), circumference (cm), 3D scanning (mls) or water displacement (mls) | Left Foot: … | Right Foot: … | Difference: … |
| | Left Hand: … | Right Hand: … | Difference: … |
| Pitting oedema Y/N | Y/ N | | |

| | | | | |
|---|---|---|---|---|
| **Cellulitis/ erysipelas Incidence:** Has the patient ever had an episode of cellulitis? (T > 38,5 / warm / pain) | Yes (complete following questions in this section) | | No (do not complete following questions in this section) | |
| Number of episodes ever | 1 | 2-5 | 6-10 | >10 |
| Number of episodes last 6 months | … | | | |

| | | |
|---|---|---|
| **Is there a disturbance to the skin surface?** (e.g. hyperkeratosis, wound, blister) | Yes (please complete the following questions) | No (no further questions to be answered in this section) |
| Is there leakage? | Yes/ no | If yes, chylous yes/ no |

| | | |
|---|---|---|
| **Classification of disability/ function *** | | |

| | | |
|---|---|---|
| **Quality of Life (adults):** Use Lymphoedema tool used in routine practice eg. LYMQOL or Lymph ICF (exist in many languages) | LYMQOL ARM or LEG<br><br>Function: …<br>Appearance: …<br>Symptom: …<br>Emotional: …<br>Overall QoL: … | Lymph ICF (0-4: no problem; 5-49: moderate problem; 50-95: severe problem >95: very severe problem)<br><br>Total score (0-100): …<br>Physical Function (0-100): …<br>Mental Function (0-100): …<br>Household Activities (0-100): …<br>Mobility Activities (0-100): …<br>Life & Social Activities (0-100): … |

| | | |
|---|---|---|
| Generic QoL Tool – EQ-5D-5L | Mobility (0-4): …<br>Self Care (0-4): …<br>Usual Activities (0-4): …<br>Pain / Discomfort (0-4): …<br>Anxiety / Depression (0-4): …<br>Health today (0-100): … | |
| **Quality of Life (children)**<br>Use Lymphoedema tool used in routine practice eg. LYMQOL, Lymph ICF for children with age 13-17y<br>(Note: if ILF Children Questionnaire (1-12 y) is available, the outcome document will be updated) | LYMQOL ARM or LEG<br>Function: …<br>Appearance: …<br>Symptom: …<br>Emotional: …<br>Overall QoL: … | Lymph ICF (0-4: no problem; 5-49: moderate problem; 50-95: severe problem >95: very severe problem)<br>Total score (0-100): …<br>Physical Function (0-100): …<br>Mental Function (0-100): …<br>Household Activities (0-100): …<br>Mobility Activities (0-100): …<br>Life & Social Activities (0-100): … |
| Generic QoL Tool – PedsQL; filled out by parent, age 1-12y | Physical functioning<br>Physical symptoms<br>Emotional functioning<br>Social functioning<br>Cognitive functioning | |

# Contributors

## This document was validated by the Paediatric and Primary Lymphoedema (PPL) Working Group.

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**HCP member before Brexit, January 1st, 2021*

***Cooperating Guest*

European
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Network

VASCERN

Gathering the best expertise in Europe
to provide accessible cross-border healthcare
to patients with rare vascular diseases

VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million concerned). These include arterial diseases (affecting aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently gathers 48 expert teams from 39 highly specialized multidisciplinary HCPs, plus 6 additional Affiliated Partner centers, coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realise the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

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**Date: June 2025**

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