



**European
Patient
Advocacy
Group**

Best Practice Cellulitis Flowchart for patients with lymphedema

Pediatric and Primary
Lymphedema Working Group -
VASCERN

Points to cover



- Introduction to VASCERN and Pediatric & Primary Lymphedema Working Group
- About lymphedema
- About cellulitis
- Flowchart
 - Idea generation
 - Method of work
 - Process
 - Dissemination
 - Next step
 - Summary

Meet us



Manuela Lourenço Marques
ePAG deputy Co-Chair for PPL
and LINFA - Portugal

Pernille Henriksen
ePAG Co-Chair for PPL
DALYFO - Denmark



Rare Multisystemic Vascular Diseases

48 expert teams from 39 highly specialized multidisciplinary Healthcare providers (HCPs)
PLUS 6 Affiliated Partner Centers

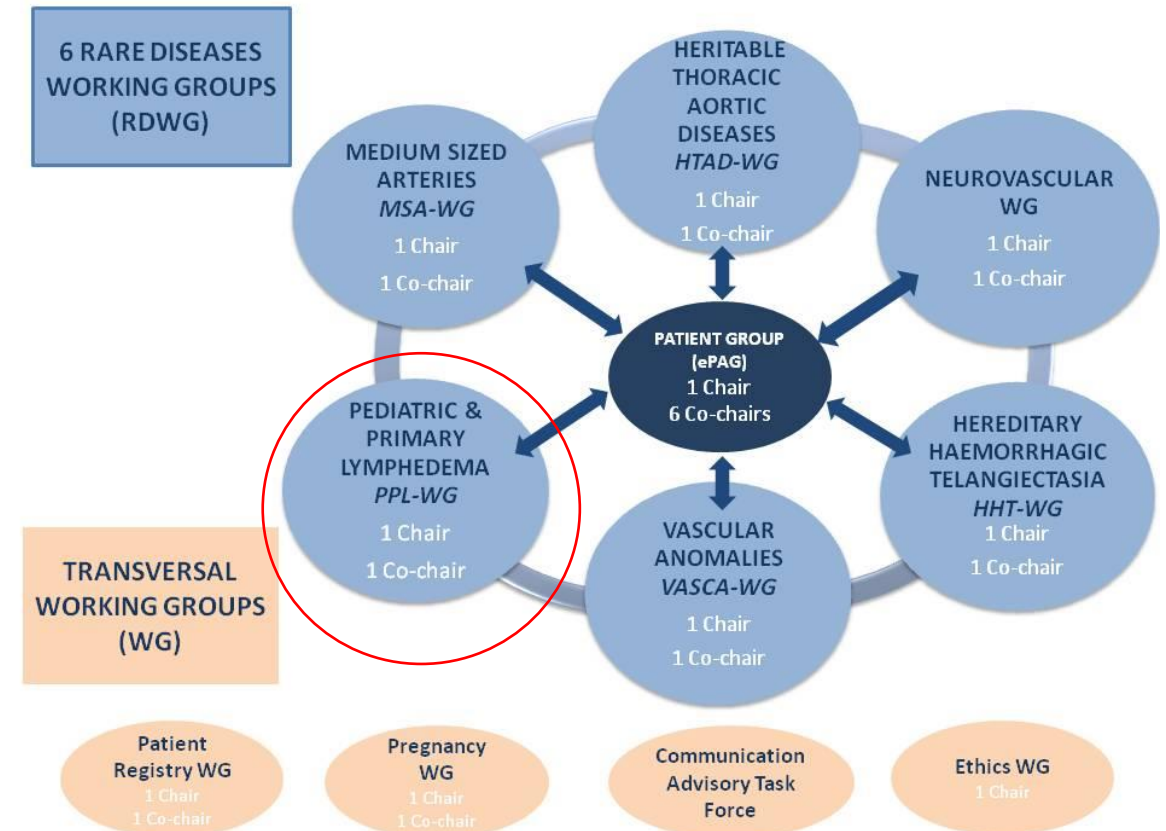
Coming from 19 EU Member States

Over 70 Patient
Organisations from all
across Europe



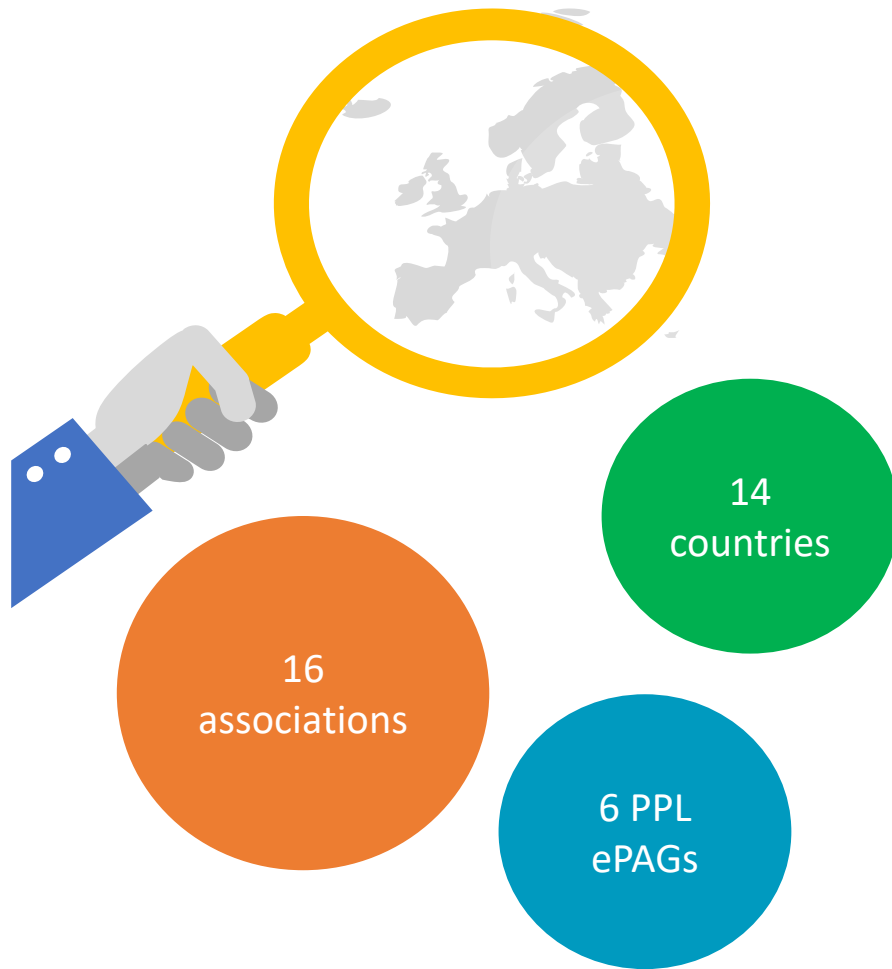
VASCERN

- 6 working groups
 - PPL
 - MSA
 - HTAD
 - HHT
 - VASCA
 - Neurovascular - new
- 4 Transversal working groups
- HCPs
 - 20 countries covered incl. affiliated partners and UK



Pediatric and Primary Lymphedema

ePAG advocates and community



Associação Nacional de Doentes Linfáticos (andLINFA)

Portugal

Association Vivre Mieux le Lymphoedème (AVML)

France

Bulgarian Association Lymphedema

Bulgaria

Dansk Lymfødem Forening (DALYFO)

Denmark

KIF11 Kids e.V.

Germany

Lega Italiana Lotta al Linfedema Aps

Italy

Lymphido OdV

Italy

Lymphoedeme Family

France

Lymphoedema Support Network (LSN)

UK

Lymph-what-oedema (LWO)

UK

Lymphoedema Ireland

Ireland

Nederlands Netwerk voor Lymfoedeem & Lipoeedeem (NLNet)

The Netherlands

Norsk lymfødem- og lipødemforbund (NLLF)

Norway

Suomen lymfayhdistys

Finland

Svenska Ödemförbundet (SÖF)

Sweden

The Faroese Cancer Society

The Faroe Islands



Pediatric and Primary Lymphedema ePAG advocates



**Pernille
Henriksen**

Dansk Lymfødem Forening
(DALYFO)

Co-chair



**Manuela
Lourenço Marques**

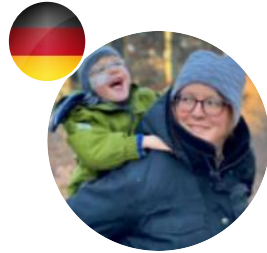
Associação Nacional de Doentes
Linfáticos (andLINFA)

Deputy co-chair



**Eline
Hoogstra**

Nederlands Netwerk voor
Lymfoedeem & Lipoedeem (NLNet)



**Carina
Mainka**

KIFTI Kids e.V



**Elena
Matta**

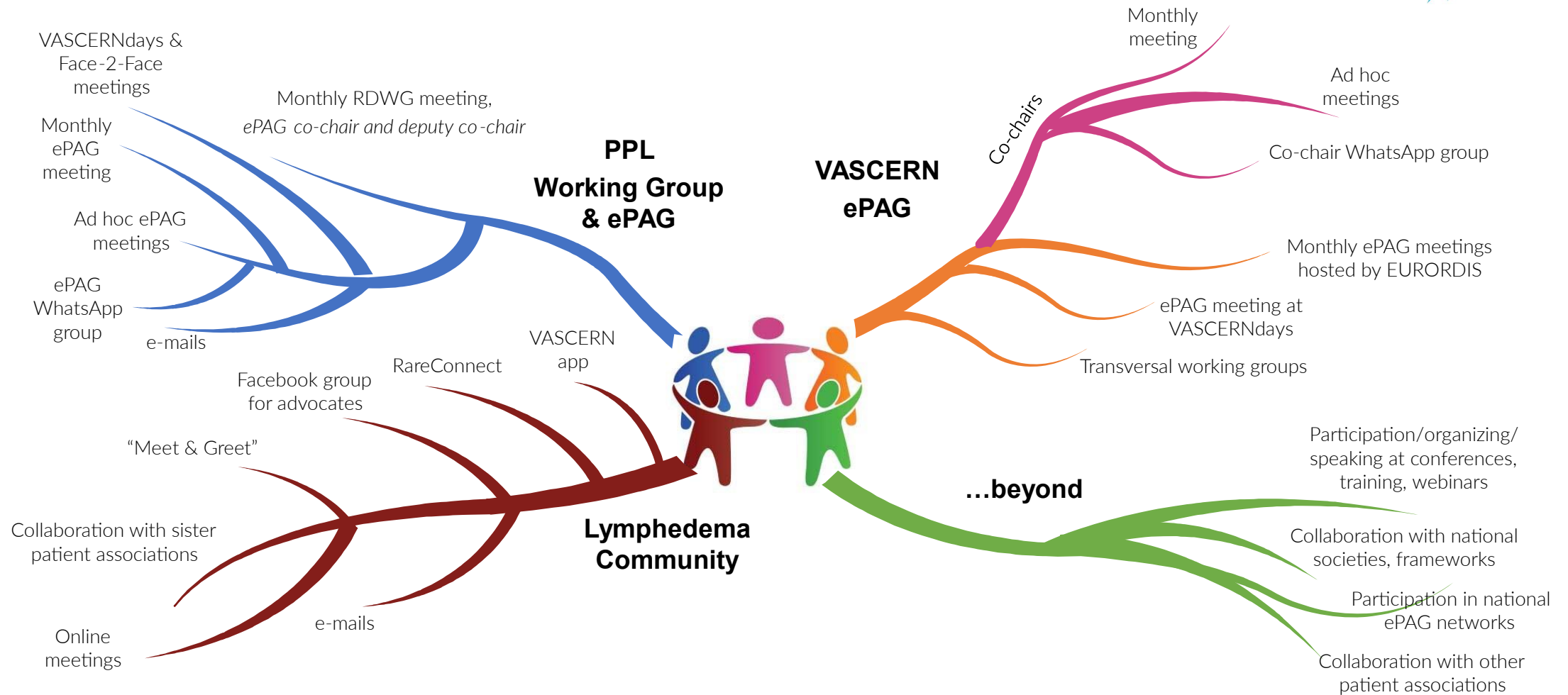
Lymphido Odv



**Alain
Pradel**

Association Vivre Mieux le Lymphoedème
(AVML)

Method of work and communication

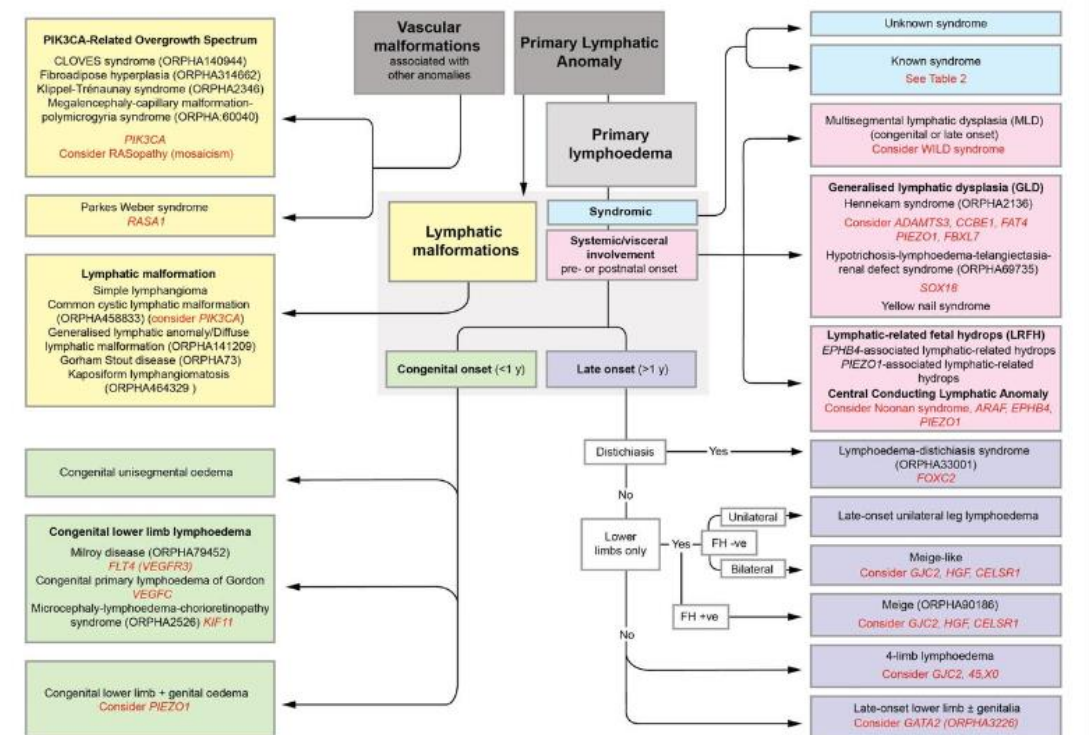


About lymphedema



- Lymphedema is a **chronic** progressive disorder that occurs because the function of the lymphatic system is impaired.
- Lymphedema appears as a **persistent swelling** of the arms and/or legs in particular, but can also be present elsewhere on the body – one or more body parts or limbs can be affected.
- The disease is divided into primary and secondary lymphedema.
 - Primary lymphedema is a rare disease

St George's classification algorithm of primary lymphatic anomalies



We are patients with lymphedema



Pascal w/ Milroys as a child
@primarylymphedema



Leonor
from Portugal



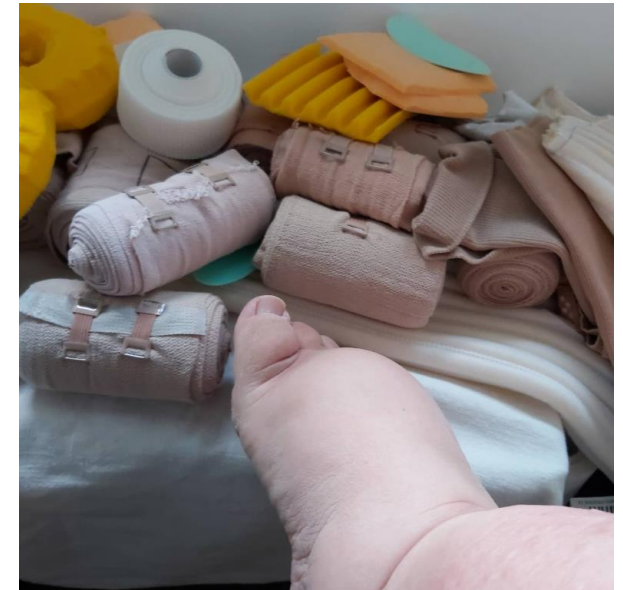
Mimi
from France
@mimi_lymphielife



Paul w/ KIF11
from Germany

Treatment

- There is no cure for lymphedema
- Treatment consists of daily management
 - skin care, compression, exercise, manual lymphatic drainage, keeping a healthy weight, for some a special diet is required
- surgery



What is cellulitis/erysipelas

- Cellulitis - **a common, potentially serious bacterial skin infection.**
- Children and adults with lymphatic impairment have a much higher risk of developing cellulitis/erysipelas.
- The clinical signs of erysipelas are: high fever (39-40°C) of sudden onset, with rigors, a 'flu-like' or unwell feeling, followed by redness, warmth, and increased volume of the affected limb.



Scope of problem

Previous episodes of cellulitis are associated with a higher risk for recurrence

Al-Niaimi, 2009

For primary lower limb lymphedema: male sex, greater body mass index, and younger age at lymphedema onset were associated with cellulitis.

Vignes S., 2022

Lymphoedema has been shown in several studies to be the strongest risk factor for cellulitis

Al-Niaimi, 2009

A cross-sectional study (40 sites) in 9 countries. N=7477
(adults with uni- or bilateral chronic edema)
15-78% had cellulitis within the last 12 months

Burian E., 2021

From the patients

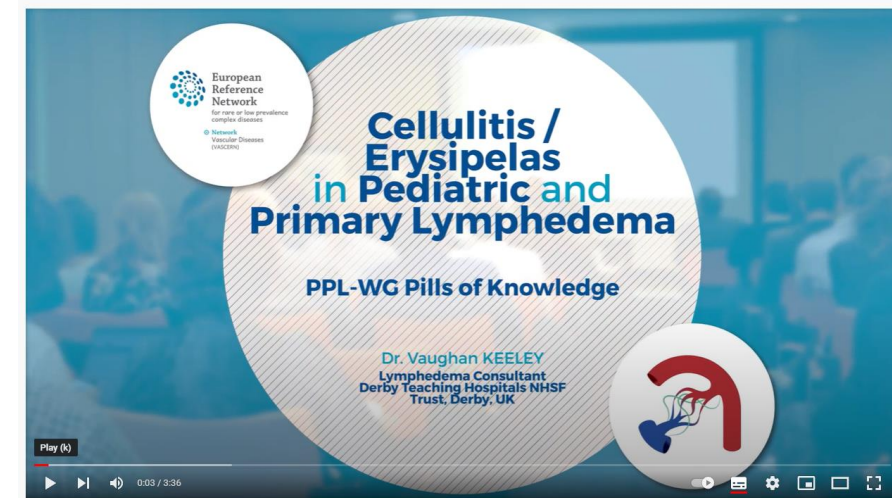
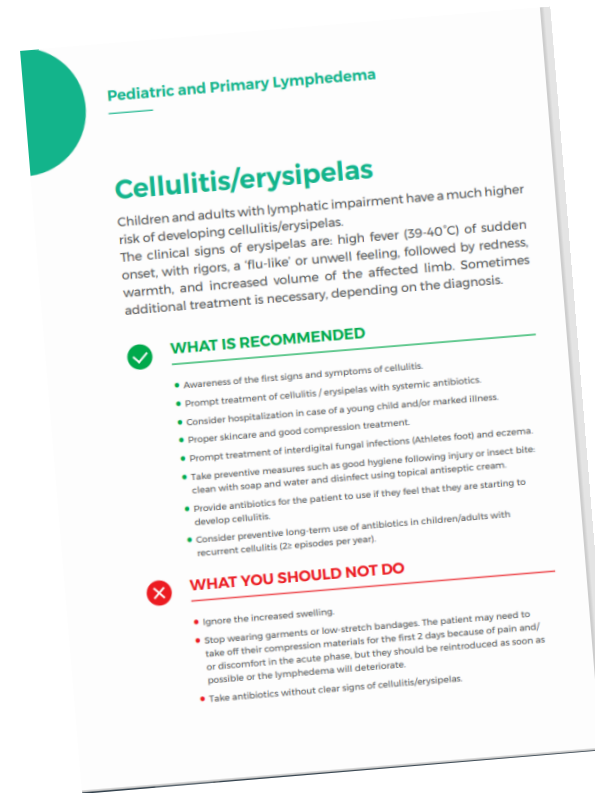
- DALYFO - Denmark
 - 61% of those answering a poll (n=77) in a Facebook group who had not had cellulitis said they had **not been informed** by their primary doctor/therapists about the risks of cellulitis
- KIFTI – Germany
 - 13 parents with children up to 8 years
 - **Worried a lot about the risk of cellulitis**: n=10
 - Had been informed about the risk by their doctor: n=3
 - Found information online: n=10
- andLINFA – Portugal
 - 80% of those answering a poll (n = 29) said they were **afraid of getting cellulitis**
- Dutch patient journey
 - by ePAG Eline Hoogstra, n=35
 - 43% had experienced cellulitis
 - **29% had experienced cellulitis ≥ 10 times**



**European
Patient
Advocacy
Group**

Collection of assets about cellulitis

- Pills of Knowledge
- Dos and Donts
 - Cellulitis
 - Skin Care
- Webinar

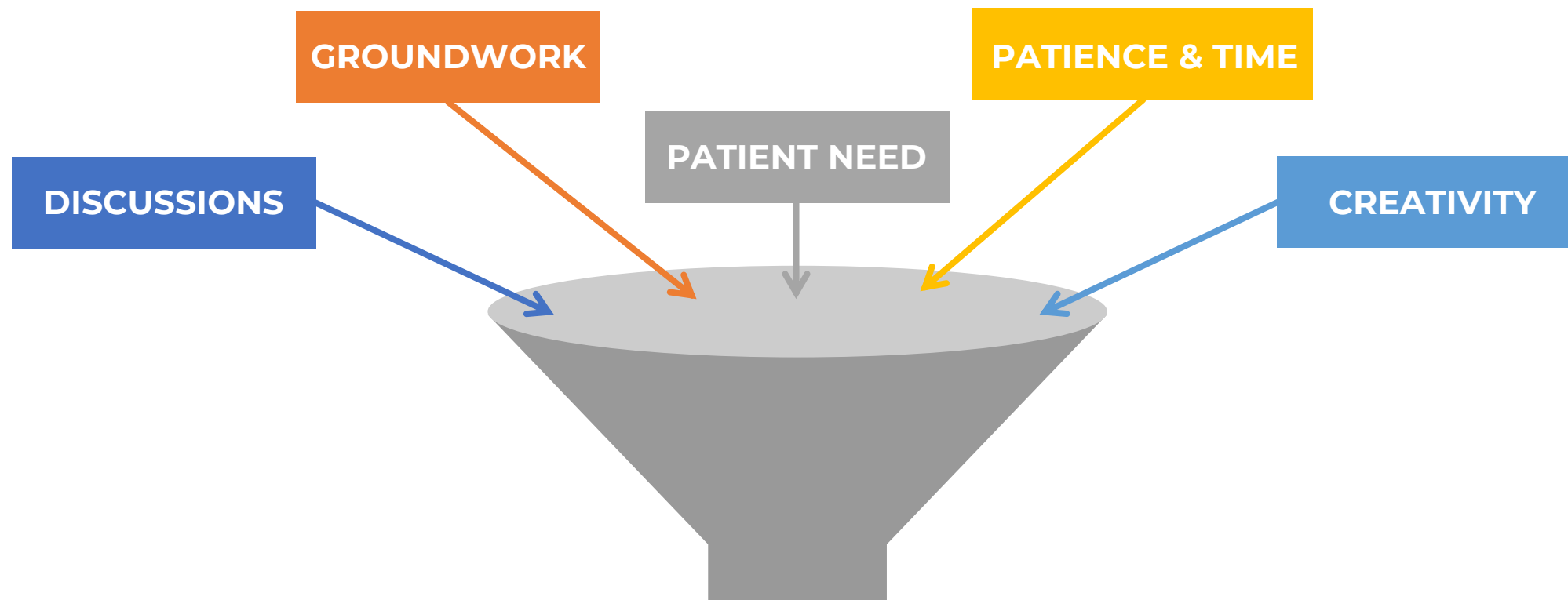


So what was missing?

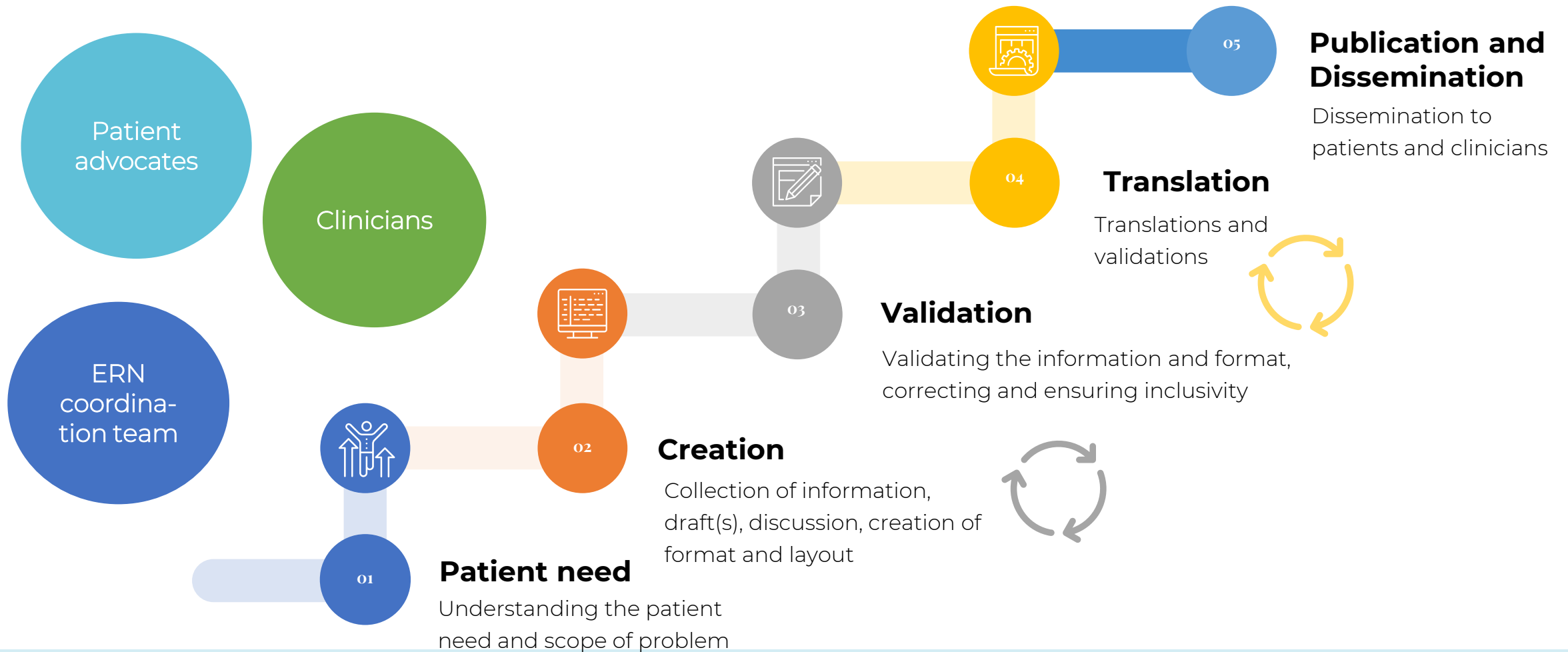
- Something that combined all the most important information
- “Tangible” – bring in the handbag and for travelling
- Easy to read
- Addresses myths
- In local language



From a patient need to a flowchart



Process



Collaboration Clinician – Patient to ensure.....



**MEDICALLY
CORRECT**

EVIDENCE BASED

UP TO DATE

RELEVANT



INCLUSIVE

NEEDS BASED

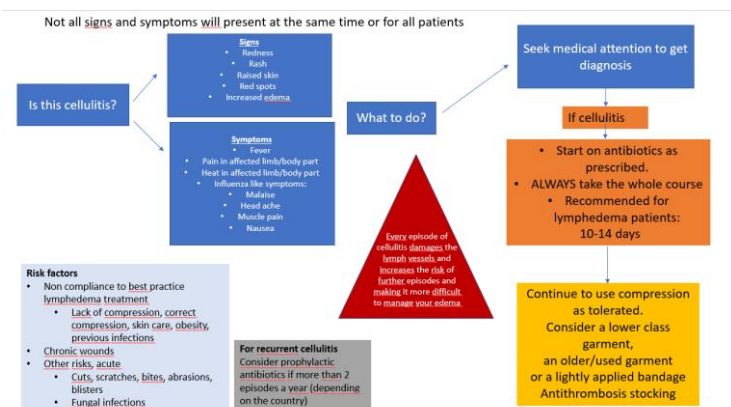
**PATIENT
CENTERED**

The creative journey

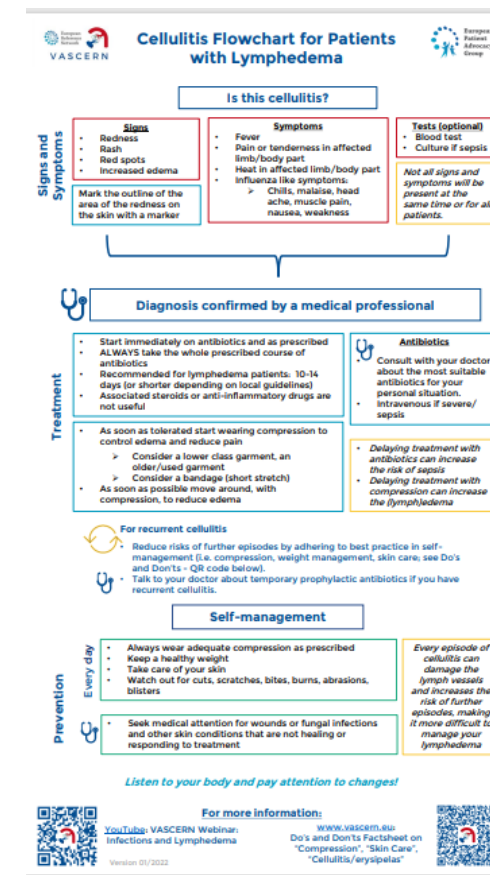
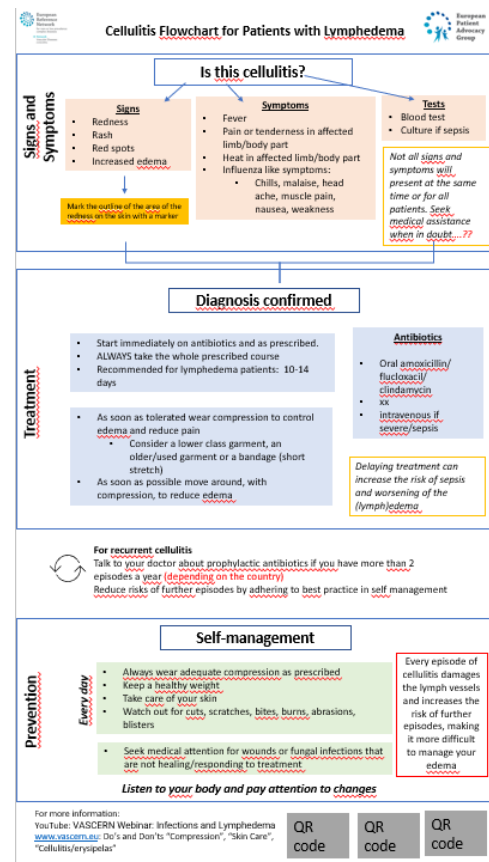
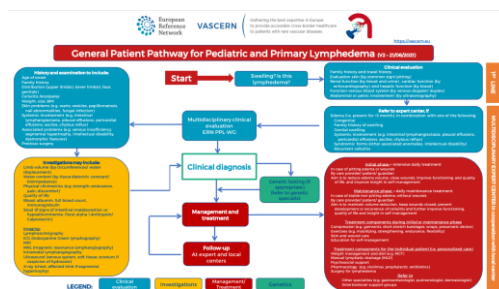
Version 1

Some version we call 2

Final version

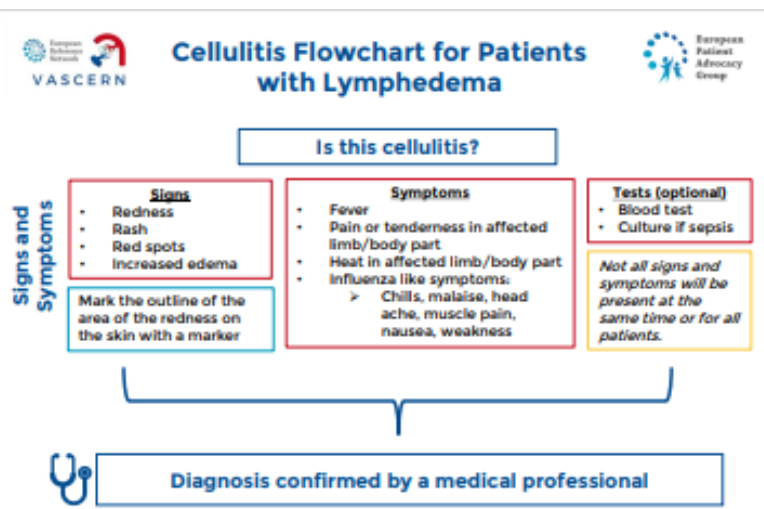


Patient Pathway

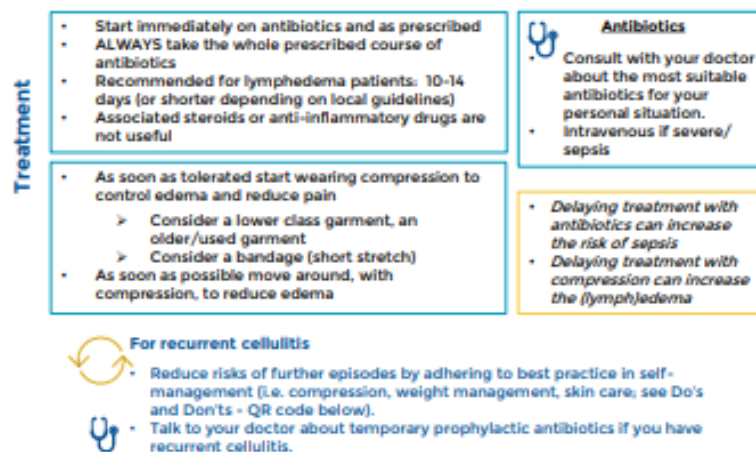


3 steps flowchart

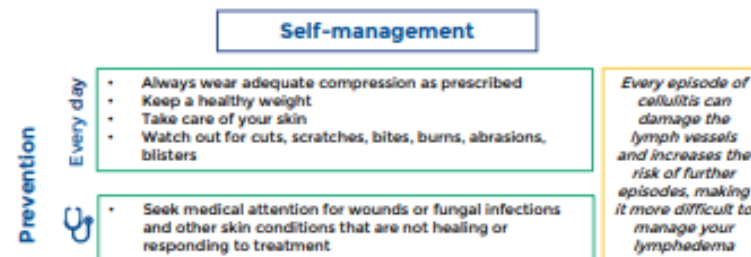
Signs & Symptoms



Treatment



Prevention



Listen to your body and pay attention to changes!




For more information:
YouTube: VASCERN Webinar:
Infections and Lymphedema

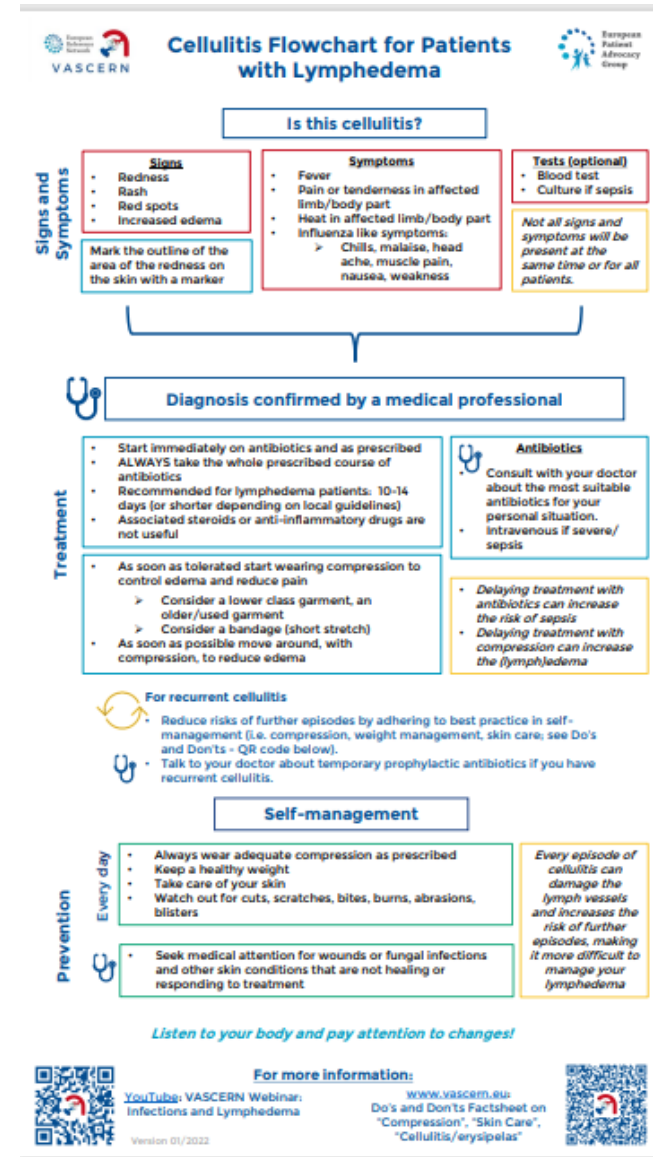
Version 01/2022

WWW.VASCERN.EU:
Do's and Don'ts Factsheet on
"Compression", "Skin Care",
"Cellulitis/erysipelas"



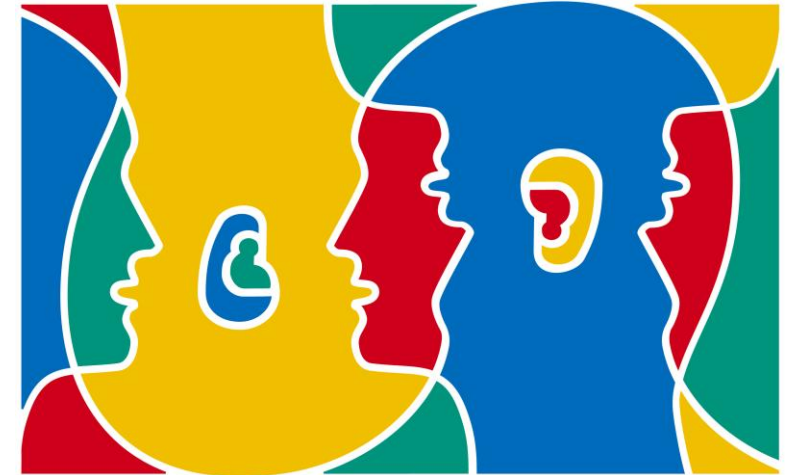
Considerations

- Layout
 - A4, 1-page
- "Language"
 - Short sentences, bulletpoints
- Translations
- Colours
- Pictogram 
- Links and QR-codes
- VASCERN (ERN) look



Language availability

- Currently available in
 - English
 - French
 - German
 - Portuguese
 - Dutch
 - Danish
 - Swedish
 - Italian
- Why do we need in so many languages?
 - Inclusivity
 - Medical terms
 - Travelling
 - Safety



Logo: European Day of Languages
www.edl.ecml.at

Dissimination – Social Media



VASCERN Facebook post
at launch

- Facebook, Instagram, Twitter, LinkedIn
 - By VASCERN coordination team
 - Of patient associations and advocates
- Facebook groups
 - Questions about cellulitis

*"Should I wear
my compression
when I have
cellulitis?"*

*"Is this
cellulitis?"*

*"Why do I
keep getting
cellulitis?"*

DALYFO LinkedIn post
at launch

Dansk Lymfødemed Forening - DALYFO
112 followers
4mo · 🌐

DALYFO har været med til at udvikle et diagram til at oplyse og informere om rosen. Diagrammet skal bruges af patienter med lymfødemed til at forstå tegn og symptomer, hvilken behandling og hvilke strategier der kan anvendes for at nedsætte risikoen for at få rosen.

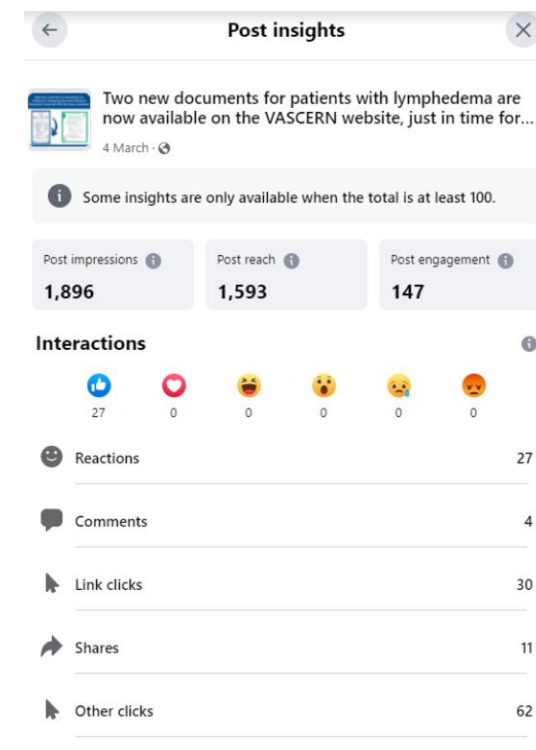
Udover dansk, findes det på flere andre sprog så diagrammet kan udskrives og medbringes på rejsen i tilfælde af, at man udvikler rosen på sin ferie.

#lymfødem #lymphedema #vascern #infections

Links:
<https://lnkd.in/g/ee29ic2a>
<https://lnkd.in/g/ePcgVWl8>

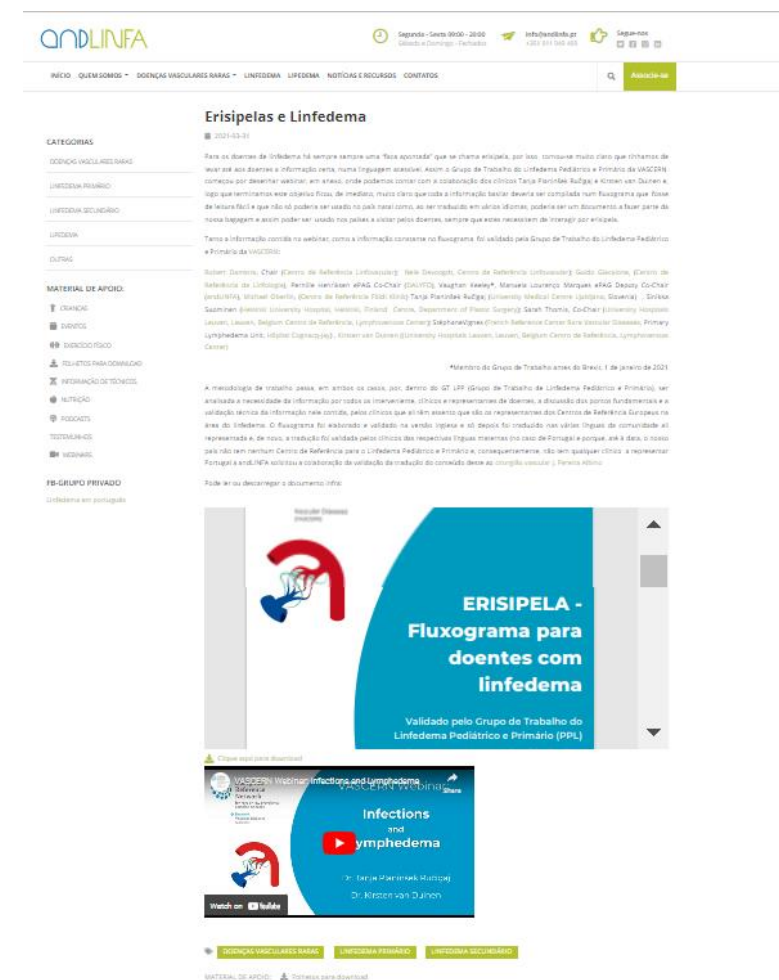
VASCERN, European Reference Network on Rare Multisystemic Vascular Diseases
See translation

The flowchart is titled 'Rosen Flowchart til Patienter med Lymfødemed'. It is divided into three main sections: 'Er det rosen/rygsplæse?', 'Diagnosen bekræftes af en læge', and 'Behandling'. The first section lists symptoms like swelling, pain, redness, and fever. The second section lists signs like redness, warmth, and pain. The third section lists treatments like antibiotics, painkillers, and compression. It also includes a section for 'Andre tegn og symptomer' like cellulitis, lymphangitis, and lymphadenitis.



Dissimination – everywhere else

- Added to websites of the patient associations
- Newsletters
- Email replies
- Present at webinars and conferences
- Hand out paper copies at patient workshops
- Encourage patients to give a copy to their GP
- Information in printed membership magazine



Next step

- Keep sharing with patients to raise awareness of both identification and prevention of cellulitis
- Review periodically
- More translations
 - Both western and eastern European languages are missing
- Part of our ongoing awareness campaign with clinicians on the risk and connection with lymphedema

Summary

- Listen to the patients – what are the needs
- Have the goal in mind while going through the process
- Keep working on it – have patience
- Ask for opinions, suggestions, corrections
- Ensure inclusivity



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Advocacy
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Thank you
for joining
us today