



European Reference Network

for rare or low prevalence complex diseases

Network
Vascular Diseases
(VASCERN)

Coordinator
Assistance Publique-
Hôpitaux de Paris, Hôpital
Bichat – France

Working Group : Paediatric and Primary Lymphoedema

Outcome Measures for Treatment Meeting

Friday 19th January 2018 08.30 – 16.30

Attendees :

Prof Vaughan Keeley

Dr Ruth England

Katie Riches

Dr Sarah Thomis

Prof Nele DeVoodgt

Invited Guest: Prof Isabelle Quere



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Member
Derby Teaching Hospitals
NIIS Foundation Trust –
United Kingdom



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UZ Leuven – België

Agenda :

1. Outcome measures for adults

- a. Limb volume measurement : Perometry, circumferential measurements, ?water displacement
- b. Cellulitis Incidence: No. of episodes, commencement / continuation of antibiotic prophylaxis
- c. Quality of Life : tools – e.g. LYMQOL, Lymph ICF.
 - i. Which to use in the ERN ? One, both or to map the questions / domains.
- d. Presence of wounds / healing? ?not appropriate in primary / paediatric
- e. Others ?

2. Outcome measures for children

- a. Comparable outcomes with the adult group?
 - b. How to measure limb volume? Is bioimpedance an alternative ? Others?
 - c. Consideration of age: different outcomes or tools depending on the child's age ?
 - d. Quality of Life:
 - i. LYMPHOQOL (IQ)
 - ii. Brief review of current literature of QoL tools for children (KR)
3. Frequency of measurements?
4. Demographic data? Minimum dataset? Treatment?
- e.g. age, diagnosis, gender, ?comorbidities, BMI (in adults?), treatment given
5. Other considerations

KR / VK 15 Jan 2018