

# LYMINF.ladies <sup>1</sup>

## Retrospective cohort study 2022

### 1- WHY - BACKGROUND

- Lymphedema is underestimated
- Infections rate is not known
- Need early detection of the infections
- Infections need to be treated earlier
- Awareness of infections for Health Care Professionals and cervical cancer patients

→ Couldn't find research on this topic

### 2- WHAT - OUR QUESTION

**What is the frequency of infections possibly related to lymphodemia after primary treatment amongst cervical cancer patients whether they received any surgery and/or (chemo) radiation ?**

### 3- FOR WHOM - STUDY POPULATION

#### **INCLUSION CRITERIA**

- Cervical cancer patients
- Developed lymphodemia
- Patients from Europe
- Diagnosed with lymphodemia in hospitals
- Diagnosed in hospitals in the last 6 months
- Lymphodemia Stage 1≤
- Cervical cancer relapses

#### **EXCLUSION CRITERIA**

- Has no diagnosed lymphodemia
- People with primary lymphodemia
- Lipedema
- Edema
- Autoimmumne disease
- People with additional cancer

### 4- HOW

#### **2 surveys :**

- first baseline at the beginning
- second survey repeated every 2 months

Outside of the clinics → online survey

#### **Motivation for patient :**

- Voucher of 50 euros in supermarket every 2 months)
- Keep contact regularly by phone and by email by support team

during 5 years :

- 1 year preparation (protocol writing, ethics, preparation, writing of inform content..)
- 1/2 years recruitment : baseline and survey/questionnaire every 2 months
- Long of observation 2 years
- 1 year to analyse data

## **SURVEYS**

### **BASELINE**

Age

BMI/Weight

Demographics

- Education
- Marriage
- Family
- Social economic
- Racial group

Primary cancer diagnosis

- What
- When

Primary cancer treatment

- When
- What
- Country

Lymphodemia diagnosis

- When
- How
- Severity
- Where (anatomically)

Access to lymphodemia treatment

### **REPEATED SURVEY**

#### **All questions (since last survey)**

Treatment for lymphodemia

- Including physiotherapy massage, compression,..
- Adherence (do you comply with treatment)

Severity of lymphodemia (standard)

BMI/Weight

Activity level

Symptoms of infection

- Set of symptoms (checklist)
- When
- How long
- How often
- Where

Treatments for infection (timing and type)

Hospitalization

#### **5- WHERE**

Patient flow

- where cervical cancer is diagnosed and departments or centers where lymphodemia is cared
- Doctors/ physical therapists/ treaters
- Patient seen

#### **6- HOW MANY**

Questionnaire should be filled out by at least 50% of 1000 patients from European countries

#### **7- WHO - STUDY TEAM**

- 6 ENGAGE's representants
- Anne Appelt
- 2 onco specialists in cervical cancer
- Physical therapist
- Statistician
- Dermatologist
- Hematologist
- ENYGO doctor
- PAG in Lymphedemia